Strengthening Parent Carer Participation

The national picture, April 2014 to March 2015
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 also 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 represent the voice of parent carers in their regions, 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 are developed locally, regionally, and nationally.
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For the first time, parent carer forums are referenced in statutory guidance.
1. Introduction

2014/15 has been a hugely significant year in the world of parent carer participation. The culmination of the Special Educational Needs and Disability (SEND) reforms was finally realised in the implementation of the Children and Families Act on 1st September 2014 and the SEND Code of Practice. Parent carer forums have worked tirelessly with their local authorities and health partners. The National Network of Parent Carer Forums alongside Contact a Family has worked with the Department for Education to ensure the legislation and statutory guidance truly reflects the changes that parent carers and children and young people feel will improve their lives moving forward.

For the first time parent carer forums are referenced within the statutory guidance Special Educational Needs and Disability Code of Practice and strategic participation of parent carers is an underpinning principle of the Children and Families Act. This public and legislative support for parent carer participation is a significant development and helps to further strengthen and underpin the benefits and value of effective participation and co-production.

Alongside the increased impetus for local authorities and health partners to work with parent carers and young people both strategically and individually comes an increased demand on those active parent carer representatives and forum members. Recognising that this period has provided both opportunities and challenges is important. The continued successes that have been achieved, often in the face of difficult situations is even more impressive.

But we know that this is not the end of the journey. The SEND reforms have given a specific focus for forum activity but the changes the reforms are trying to bring about are cultural and attitudinal changes which don’t happen overnight, or even over a few years. Cultures are built over years and changing long held attitudes and values can be difficult. Change can be slow, and for many parent carers who are forum members, who have committed so much of their time and energy, these changes are not to benefit them or even their own children in some cases, but for those children and families who will come behind them. For that the sector and our communities owe much to the dedication and commitment of these parent carers.

Forums have continued to access funding from the Department for Education through Contact a Family to support their basic functioning. The parent carer participation grant - £15,000 available to each local forum – has been invaluable in providing a basic level of funding to support activity. Some forums receive additional funding through their local authority, health partners or through charitable or trust funding. But for many forums this basic level of direct Departmental funding is their only funding that enables them to continue. The fact the the Department continue to fund forums in the challenging economic climate that we are in demonstrates the value and significance that is placed upon their activity, involvement and co-production.

The information provided in this report is based on both the grant monitoring data from 2013/14 and from the grant application forms from 2014/15. Comparison to the previous years data also helps to demonstrate the progress and challenges that parent carer forums face.
Contact a Family, working closely with the National Network of Parent Carer Forums (NNPCF), has valued the opportunity to support and develop the parent carer participation agenda. We are pleased to continue to be the Department for Education’s delivery partner for 2015/16 and look forward to working with parent carer forums and their strategic partners over the coming year to embed the active participation and co-production of parent carers in the decisions and planning made about services that affect their children and families.

Sue North
Director of Operations

**KEY FINDINGS**

- Forums have increased their reach to local parent carers with forums reporting a reach to over 67,191 local parent carers.
- There has been an increase in the number of forums who receive additional funding to support their participation.
- There has been an increase in the number of forums who keep records of the diversity and demographics of their membership.
- There has been an increase in the number of forums who work in co-production with their education, social care and health partners.
- There continues to be a decrease in the number of forums who have a paid participation worker.
“The voices of parent carers are making a difference in our local communities and shaping national policies.”

Attendee at the National Event
2 Feedback from application forms 2014/15

(including comparison with 2013/14 applications)

150 areas received the parent carer participation grant funding in 2014/15. Two areas did not apply for the grant. Contact a Family holds the grant on behalf of five areas where there are particular challenges or issues. These areas are included in the figure for parent carer forum supported by a voluntary organisation.

2.1 Description of organisation

73 forums (48%) described themselves as independent parent carer forums, up from 70 forums in 2013/14. There was an increase in the number of parent carer forums supported by local authorities (from 11 to 16), and by parent partnership services (from 11 to 13). 33 forums are supported by a voluntary organisation, compared with 32 in 2013/14. This figure includes the five areas where Contact a Family is holding the grant. 10 voluntary organisations and five other types of organisations made up the other 15 areas.
2.2 Forum status

The number of forums which are registered charities again increased, from 26 in 2013/14 to 28 in 2014/15. Significantly more are now constituted groups (from 48 to 62). 18 have some other status, and only 23 forums now have no legal status.
2.3 Parent carer involvement

<table>
<thead>
<tr>
<th></th>
<th>2013/14</th>
<th>2014/15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of parent carers for whom you have contact details, the number on your database or the number asking to be kept informed about participation</td>
<td>63,336</td>
<td>67,191</td>
</tr>
<tr>
<td>Number of parent carers on management/steering groups involved in running the parent participation work/forums</td>
<td>1,449</td>
<td>1,386</td>
</tr>
</tbody>
</table>

In 2013/14, forums reported that a total of 63,336 parent carers had provided contact details, were stored on the forum database or had asked to be kept informed about participation. This has risen by 6% during 2014/15 to 67,191. This increased reach is also reflected in the response to the question ‘approximately how many parent carers input their experience of services to the parent carer forum?’. This rose by 20% between 2013/14 and 2014/15 to 34,367.

The number of parent carers on management or steering groups involved in running the forum continues to decline, albeit by only 4% to 1,386.
2.4 Other financial support for parent carer participation

There is an increase in the number of forums receiving additional funding which is positive to know and demonstrates the value being placed on forum activity.

2.5 Source of additional funding

At the start of 2013/14, forums had access to additional funding totalling £1,029,042. This was a decline from 2012/13 (£1,254,336). However, the amount of additional funding available has risen to 2012/13 levels and was £1,293,771 at the start of 2014/15. Whereas almost the same number of forums received additional funding up to £10,000 (35 in 2013/14, 36 in 2014/15), there was an increase in the number of forums which had additional funding in excess of £20,000 (15 to 19).
2.6 Participation workers

The number of areas where a participation worker is employed continues to reduce. There were 60 in 2012/13 and 56 in 2013/14. This has fallen further to only 49 areas in 2014/15. Of these, 35 said they worked exclusively with families of disabled children (down from 42 in 2013/14).

2.7 Additional resources
– payment to parent carers

In 2013/14, 46 forums said that their local authority or health provider made payments to parent carers who sit on strategic decision-making boards or committees. This has dropped slightly to 42 areas in 2014/15.

2.8 Additional resources
– support in kind

The provision of support in kind, such as photocopying and the use of meeting rooms, continues to fall, from 88 areas in 2012/13 and 84 areas in 2013/14, to only 75 in 2014/15.
3 Feedback from monitoring forms 2013/14

This data represents information from 147 parent carer forums who submitted their grant monitoring form. 2 areas did not receive a grant in 2013/14, and a further 3 did not submit a completed monitoring form in time for this report for a range of reasons. In addition, not every form was fully completed, nor every question relevant to every forum, so the total in each graph or table does not necessarily represent the total forum response.

3.1 Steering group, parent carer representatives and forum members

There seems to have been a change in the number of people involved with their parent carer forum at a steering group level. In 2012/13, slightly more forums responded that they had 11 to 15 steering group members, ahead of the 6 to 10 members category. But in 2013/14 the 6 to 10 members category was by far the largest. However, there was a significant increase in the total number of forums which responded to this question, making year-on-year comparisons less meaningful.

Forums reported a total of 1,386 steering group members.

<table>
<thead>
<tr>
<th>Number of Members</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-5 members</td>
<td>21</td>
</tr>
<tr>
<td>6-10 members</td>
<td>79</td>
</tr>
<tr>
<td>11-15 members</td>
<td>30</td>
</tr>
<tr>
<td>16-20</td>
<td>5</td>
</tr>
<tr>
<td>20+ members</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>141</strong></td>
</tr>
</tbody>
</table>

It would be fair to say that forums have become increasingly challenged to recruit and maintain steering group members for a wide range of reasons.
3.2 Engaging with parent carers and other groups

**Recording of diversity of parent carer members**

When we first asked this question, a number of forums responded by saying they did not collect this data, and felt it was intrusive and off putting to ask parent carers to disclose or declare this. Within the monitoring forms, we provide explanation of why we believe collecting this type of data is important for forums to be able to demonstrate their reach, and identify groups of parent carers who may not be inputting their experiences to the forums. This refers to diversity in the broadest sense.

We were therefore pleased to see an increase in the numbers of forums who now collect this type of data. This has increased from 45% of forums in 2012/13 to 49% of forums in 2013/14. This is still, however, less than half of forums and we continue to advocate the benefits to forums of collecting this data.
73% percent of forums keep a record of the demographic details of their membership and steering group.
3.3 Annual record of membership

In 2012/13, 70% of forums said that they kept a record of demographic details of their membership and steering group. This rose to 73% of forums in 2013/14.

3.4 Impairment type

Forums were asked if there was an impairment type represented by a significantly greater number of members of the forum. 70% said yes in 2012/13; this has remained fairly constant at 69% in 2013/14. Austistic spectrum disorder (ASD) was the impairment type that predominated.
3.5 Links with other groups

Forums were asked if they send information to and link with other groups of parent carers and organisations that support disabled children in their area. In both 2012/13 and 2013/14 all except a very few forums said yes.

At the other end of the scale, a handful of areas still report they have no working relationship with their education authority, although far fewer report that they are only informed (down from 13% in 2012/13 to 8% in 2013/14). The same proportion (9%) report that they are consulted.

3.6 Joint working

In education, joint working continues to develop. In 2012/13, 36% said that they worked in participation with their education authority, and 36% in co-production. In 2013/14, there was a leap in the areas where co-production was used, up to 57%. Overall, 82% of forums said they worked in either participation or co-production with their education authority, compared with 72% overall in 2012/13.
SOCIAL CARE 2013/14

As with education, the trend in social care is towards co-production. Areas where this is the approach has increased from 38% in 2012/13 to 40% in 2013/14. However, overall, the figure for participation and co-production combined has not significantly changed (73% in 2012/13, 74% in 2013/14). 4% of areas still report no working relationship with social care in 2013/14, as in the previous year.

HEALTH 2013/14

Working with health has also shown improvement, with an increase from 16% in 2012/13 engaged in co-production to 24% in 2013/14. Participation remained stable, however (37% in 2012/13 and 36% in 2013/14).

Perhaps significantly, given the changes in the structure and management of the health service during this time, there was a noticeable increase in the number of areas which said they had no working relationship with health in 2013/14 (7%, up from 4% in 2012/13).
3.7 Involvement with Short Breaks Services Statement

More areas reported that they co-produced the Short Breaks Statement with their local authority (up from 39 areas in 2012/13 to 46 in 2013/14). Areas which participated in this also showed a significant increase, from 26 to 39 in 2013/14. However, similar numbers of areas reported that they were consulted and were involved in reviewing, or only consulted.

Disappointingly, there was an increase in the number of areas who said they had no involvement in the development or review of the Short Breaks Statement for their area (up from 5 in 2012/13 to 15 in 2013/14), and 6 said they had not seen their statement (up from 4 in 2012/13).

3.8 Local offer

The extent to which forums have been involved with developing their area’s local offer has improved greatly from 2012/13. In that year, 32 areas reported no involvement or only consultation on the local offer proposal. This dropped to 18 areas in 2013/14. At the other end of the scale, whereas only 41 areas reported that they co-produced their local offer with the local authority in 2012/13, this jumped to 75 areas in 2013/14.
3.9 Regional network meetings

Forums have the opportunity to meet at least once a term with other forums in their region. This is an opportunity for them to share experiences, hear updates from their NNPCF regional representative and Contact a Family advisor and to feed back their views. The numbers who attend remains fairly constant, dropping fractionally from 80% in 2012/13 to 79% in 2013/14.

Some regions have moved to a cluster model approach to address travel and geographical issues and have tried using technology to enable participation from those not able to travel. As a key resource to enable peer support, and the sharing of information, we are keen to ensure that forums are able to attend meetings. However, the same issues are often identified as barriers, and there are no easy solutions to these. They include:
“This has proven difficult in the past, however we have recently had a change in our structure that has identified members who will have a better opportunity to attend.”

“We are trying to attend but due to school, work schedules we were unable to attend. We have used Skype once and will continue to do this on a regular basis.”

“Often the dates have clashed with our own events. The distance of the events can be a problem and can make it difficult to attend due to the need to be home for school.”

“Distance to travel to the regional meetings which are held in the North East makes it prohibitive to have regular attendance. The costs in time and financial commitment within a very limited budget have restricted the number of regional meetings the steering group members will attend.”

“In 2013 we attended as many meetings as possible, and will continue to do so in 2014.”

“The weather has affected our ability to attend the regional meetings. We remain in contact with our regional representative and our regional adviser from Contact a Family.”

“The distance is a big problem especially with child care but we have been involved, along with other forums in using Skype to feed in to regional groups with varying success but technology could be used to make all groups more effective.”

“If we can access them due to locality and timings (school runs/caring commitments)”

“We constantly struggle with capacity as not all forum members feel comfortable attending regional meetings as representatives of the forum.”
Within the monitoring forms, we focused more on outcomes of the activity, rather than just the output and activity. This has been challenging to some forums, but all were able within their monitoring to provide examples of outcomes.

There has been a wide range of outcomes evidenced through the monitoring, with some overarching themes that continue to support the previous evidence of how parent carer participation leads to improved outcomes for disabled children, their families, and in service provision.

Key themes among outcomes include:

- better-informed and more knowledgeable parent carers
- improved service provision where there is effective participation
- better value for money services
- increased support to parent carers
- opportunities for employment for some parent carers involved in participation.

Some examples of outcomes identified by forums can be seen below.

4.1 Example from a North West parent carer forum

One of our major outcomes this year is concerning the short break provision for disabled children.

The funding had been awarded to a National Charity, whereas previously the parents had managed it, resulting in maximum funding being allocated directly for short break provision. Sadly, the available activities and respite funded by the short break funding were cut and families found they had fewer choices.

Parents from the forum decided to challenge the local authority and contacted the commissioner directly asking for explanations as to why things seemed to have taken a backward step. Our parents kept up the pressure, and a review was carried out with families fully involved in the consultation process.

The parents’ voices were listened to as it was announced at the Local Offer Parent Forum Event that the existing contract will not be renewed. The new commissioner has begun to build a rapport with parents, building trust and confidence and it is indicated that the short break service will be run very differently with families’ views being the focus of change.

4.2 Example from an East of England parent carer forum

Co-producing a SEND survey with the LA has meant that the survey is better understood by parents and it now includes questions to help inform what parents really want rather than the questions the LA thought they wanted to ask.

Co-producing the survey has also helped us to establish strong relationships with LA officers we previously hadn’t worked with and made us confident to work with them on developing the Local Offer. This has helped to ensure that coproduction is the aim of both the forum and the LA in the future development of services.
4.3 Example from a London parent carer forum

We established a new pathway for engaging ‘new’ parents and refreshing the forum by working closely with Kids keyworkers and the developmental play service to find new ways of engaging parents through workshops and engagement sessions that are relevant to them. Many parents need the opportunity to build relationships with each other for peer support, then establish relationships with the participation team before they feel able or have the desire to engage with local issues. As information gathering patterns have changed the forum has worked hard to establish a core of engaged parents that reflects the population of the local community. The impact of this strategy has paid off with wider representation of BME communities, fathers and parents with more complex needs children at forums and involved in consultation.

4.4 Example from an East Midlands parent carer forum

We have successfully forged important working relationships with key professionals in all the areas of Health, Education and Social Care which has had a huge impact on future engagement and service planning. Our Meet & Greet events enabled The Forum to introduce themselves to professional partners to share our vision for the future. As a result parent participation is secured in the following work streams or focus groups:


4.5 Example from a North East parent carer forum

Outcomes from working together with our local authority:

- Information is becoming more parent/carer friendly
- The opportunity to address and do a presentation to 60 SENCO’s at their regular meeting which has resulted in us being invited into schools to speak to their parent groups. This has raised awareness.
- Continuing the co-production element of the children’s and families bill and the implementation of the SEN reform.
- Our local authority respects and acknowledges the preparation work we have undertaken by the allocation of £2000 for this specific work
- Steering group members and our network representatives have been included on the SEN Project group, local offer task and finish group, education health care plan task and finish group, personal budgets group and attend other relevant meetings around these.
- Co-production of the SEN Reform Newsletters
- Steering members now have two places on the complex needs partnership board (children’s) and the learning disability partnership boards (adults)
4.6 Example from a South East parent carer forum

Budget cuts were announced for 2015/16 which we challenged (at the Children & Young Peoples Select Committee), as a result of which there is a councillor led task & finish group looking at short breaks provision in great detail before any decisions are made. We have been invited to further contribute to their evidence and we hope this will help save short breaks and also help us develop relationships with the councilors involved as a result.

4.7 Example from a South West parent carer forum

The Wheelchair Service user review resulted in the creation of a fully transparent Action Plan on the part of the two local service providers, with regular monitoring of delivery and outcome by parents, carers and the children and young people who are using the service.

4.8 Example from a West Midlands parent carer forum

Attendance at a local university Service User & Carer Group has resulted in special needs and disabilities now being on the agenda in all mainstream health professional courses and degrees being delivered by the University - not just the specialist mental health and learning disability faculties.

4.9 Example from a Yorkshire and Humber parent carer forum

Our engagement events for families with CAMHS service managers highlighted gaps in the service, and placed these at the forefront of service development plans. Our involvement in planning a workshop for practitioners raised awareness of a range of families concerns and resulted in a consensus about the actions needed to be taken to address them.

Our event on the local education (schools) core offer meant that the views of families directly informed the development of the draft document, prior to consultation.
5 Achievements of parent carer forums

We also asked forums to tell us what their greatest achievements were over the year. Below are examples from each of the regions.

Example from a East of England parent carer forum

We are heavily engaged with the local hospital and the Clinical Commissioning Group (CCG) in their review of the configuration of the delivery of paediatric services in the county, the relationship we have developed with management at CCG has given The forum an ‘open door’ to be as actively involved in reviews and changes as our capacity allows. Our involvement in the paediatric services crisis at the hospital allowed the CCG to understand the impact on our families and was crucial to the configuration of the interim changes currently in place.

Example from a North West parent carer forum

We have really enjoyed working with our partner agencies and have all found it very mutually beneficial. It has been really positive as we all recognise that each other has their own specialist areas; for example the forum focuses on parent participation in services and policy development, The Carers Centre focuses on supporting parent carers and helping them to cope, Parent Partnership focuses on education and individual case work. We respect each other's specialisms and are happy to work together to make sure that we include the maximum number of parent carers in all of our work. Fundamentally we all want to help parent carers and the best way to do this is to work as a team which we feel we have done very effectively.

A big achievement for the forum this year is the way in which we are involved in co producing services and policy in light of the wide ranging SEND reforms coming in September 2014. We are heavily involved in the production of the local authority’s Local Offer. We also have parent reps on the preparing for adulthood panel and the high level project delivery team group.

Example from a North East parent carer forum

We took part in a Volunteer Month within the council and as a result now have 3 new parents who volunteer for us in respect of admin and office tasks.

2) We have started working with fathers who are Veterans and have disabled children. After training we are now starting to work with the Veterans to put a page on our website to signpost them to the most appropriate places for the right help and support.

3) Strengthening our relationship with the Jewish community and understanding their cultural differences. We now have a Jewish lady who attends our Forum meetings.

4) Our work in co-producing the Local Offer and testing the site before it goes live with young people and their parents together.

5) Starting a good relationship with the CCG and Healthwatch.
Example from a London parent carer forum

We contacted the Head of Learning and Achievement regarding the gap in Post 16 provision. Initially the LA didn’t want to acknowledge that a gap existed although they were sending school leavers out of the borough. The forum produced a document detailing where the gap was and what needed to be provided. This was sent to the LA and Councillors. It was eventually conceded that a Strategy Group should be organised which is led by a consultant who is also working on the Local Offer, EHC Plans and Personal Budgets. Members of the forum and LA visited similar out of borough provisions and a strategy document was produced which identified what a new provision should look like. It was presented to Cabinet who agreed to allocate funds to spend on a new provision. The strategy group consists of 3 parent forum members, representatives from current post 16 provisions, adult and children’s social care, SEN and Health and we have now been given a blank canvass to work from to design a new provision.

Example from a Yorkshire and Humber parent carer forum

The forum were involved with the tendering process of the new carer’s centre provider. This involvement was paramount and prominent as parent carers were included from the offset. The process took 12-14 months, with 5 bids to investigate and scrutinise. The interviews took place 2 months after the bids were evaluated, this was a huge responsibility to ensure we did it right.

We worked alongside the CCGs, a range of adult carer groups, young carers and the local authority, plus the contracting team; it was a successful collaboration of departments working in partnership and many relationships were formed.

The forum were extremely important and invaluable within this process as this Carers Service was for ALL carer groups and the questions the forum asked the potential bidders was key for all parent carers.

Example from a East Midlands parent carer forum

By showcasing one of our parents’ journey from angry, disengaged parent to coordinator of the work stream reps we have demonstrated our value locally when parent carers have participated in and coproduced services. We are confident that this will lead to influencing more good practice and generate strong relationships with our LA, health and education partners.
Example from a South West parent carer forum

A realisation by local SENCos that we can really help them to develop better partnership working with families, and we don’t just want to moan – we are really proud of our SENCo Helpsheet for Parents and Carers (what to expect from your SENCo and how you can help them) and our chart for SENCos concerning the 4 stage cycle (assess, plan, do, review) in the new Code of Practice, which clearly shows how parents feel they can contribute at each stage, along with 2 Principles of Partnership Working.

Example from a South East parent carer forum

We conducted a survey on school exclusions to find out the frequency of and circumstances around illegal school exclusions in primary and secondary mainstream schools. Parents were invited to respond to the survey and provide comments of their experiences. The County Council were informed of the results which were shared publicly. This survey highlighted what is happening and parents felt able to express themselves freely. The County Council will review the situation over a period of 12 months and an increased number of parents/carers are now aware of what is legal and illegal.

Example from a West Midlands parent carer forum

Our Education Health and Care Plan was created in co-production with families. Parents on the task and finish group looked at a selection of draft designs from across the country. Professionals really wanted to go with a more informal looking plan, a design featured by Early Support, however parents felt that it would not have the ‘clout’ it needed and still very much wanted a more formal looking document but with a strong focus on the personal elements ie; a one page profile and family journey. Parents worked very closely with lead professionals and played a key role in the development of the draft plan as 10 families trialled the new single assessment process. Regular meetings took place with the families to discuss changes to the plan, wording, layout etc. They were involved in the design of the front cover of the plan and felt parents should have a choice on whether a photograph of their child features in the plan. Some elements of the plan did have to change following release of the revised draft code of practice that parents were unable to influence.
6 Challenges for forums

We also asked forums to tell us about the challenges they have faced over the last year. Below are examples from each region.

A North East parent carer forum

The greatest challenges we faced in 2013/14 were keeping abreast of the changes within the Local Authority and Health Services management structures and the fact that the bulk of the work generated by the meetings, events and activities we have attended and organised has been mainly shouldered by two members of our steering group who live in the very north of our large rural county. This has put pressure both on their time and also on our ‘Out of Pocket Expenses’ budget. We feel that the geography of such counties and the challenges we face in reaching the parents/carers of children/young people with SEND should be taken into account with regard to the amount of grant money that the Forums in each Local Authority receive.

A North West parent carer forum

Not enough capacity to nurture the parents who have expressed an interest in becoming more involved in the forum.

Finding a new base for the forum.

Increasing turnover of staff in the local authority and long term sickness leading to frustration at incredibly long timescales to get things done.

A South East parent carer forum

The rise in demand for parents to participate. It was overwhelming at times, and we are amazed at how we’ve got through. The numbers of parents doing the work has risen dramatically, which is fantastic. The challenge will now be the implementation and review stages of the new legislation.

A London parent carer forum

The biggest challenges have been:

1) Capacity and managing additional workload

2) Cultural change in practice against a back drop of radical LA restructure and financial constraints across of areas and levels.

3) Getting the right parents involved whilst representing the views of all parents

4) Sustainability and cost

5) Maintaining parents’ commitment to be involved when services are being reduced.

An East of England parent carer forum

Maintaining the workload of the reforms agenda at the same time as expanding the parent participation work with families has stretched the management capacity of the Forum but has been achieved!
An East Midlands parent carer forum

Whilst challenging to say the least, we feel we have had a great effect not only of the forming of the EHC plans for the pathfinder, but have also had a profound effect upon the thinking of those involved in it in the other areas at which we meet them. Many of whom have agreed that although they have been working in the field of DC&YP’s they’re thinking on their ‘clients’ often bore no relation to that of the parents, carers and the children themselves. We are now well established in the thinking of our LA and are often asked to participate in consultations etc before we become aware of any potential need for it.

Our LA like others have clearly been impacted by central government’s constraints on their budgets which has had an effect on staff and the levels of services they can maintain and the changes from PCT’s to CCG’s has meant a few losses in staff that we had developed good relationships with.

A West Midlands parent carer forum

LA funding crisis led to the withdrawal of some key services, and the imposition of charges for some services that have been free to date. This process is continuing and causing great uncertainty for staff and parent carers.

Aligned to the budget cuts, is the constant churn of LA staff, and added demands on Council following a poor OFSTED safeguarding inspection.

The feeling that though Parent Carers are more involved, it is still tokenistic. Parent Carers were involved in the commissioning of Short Breaks and wrote the outcomes, but the way the LA structured the interviews made it very hard for Parent Carers to play a full part in the contract evaluation. The legal team insisted that the same person be present for all three days of each stage of the contract evaluation from 9 am – 5 pm! This is a very big ask of volunteers.

A South West parent carer forum

Challenges as always were being able to find the time in amongst our family lives to achieve everything we wanted to.

This year has proven a challenge due to some difficult experiences relating to steering group management. However with the support of the Children’s Commissioner and advice from Contact a Family this was resolved in a very amicable manner and we look forward to the future.

A Yorkshire and Humber parent carer forum

Trying to straddle the line of working in participation and co production whilst hearing the very challenging experiences of our families, frustration at the system and the cuts the government placed upon the LA that means valuable colleagues have left the service, redundancy etc.
7 The national support offer for parent carer forums

All parent carer forums continue to be able to access the core offer of support from Contact a Family. This includes telephone and email access to a named parent carer participation advisor, access to learning and development opportunities, regular communications, and the opportunity to engage with the regional network, which advisers are invited to attend.

We currently employ four full-time equivalent regional parent participation advisors, although have five advisers who work across the nine regions of England. Their role is to be the first point of contact for all parent carer forums in their regions. They offer advice and support via telephone and email, and visits where appropriate. They also support and attend regional meetings of the NNPCF, support forums with their grant applications and monitoring submissions and arrange and attend local training events.

From April 2013 to February 2014, approximately 7,028 hours of support have been provided to parent carer forums by the regional parent carer participation advisors.

Advisors are the first point of call for forums with any queries, concerns, or challenges with either their grant applications, monitoring, or the work of forums. Forums told us that this highly-valued resource is one of the support provision they would want to sustain.

7.1 Associate support

Forums that require additional, individual or targeted support are offered this through our pool of 30 associates.

Sustaining and developing parent carer participation is extremely demanding, especially when much of it is reliant on the support of parent volunteers with often very challenging personal lives. Inevitably therefore some forums will occasionally need some enhanced support to help them through any difficult patches.

So that forums in need of enhanced support get dedicated time from one individual we retain a small number of highly skilled individuals, associates, who can work closely with forums, local authorities and health partners on specific problems.

This year 42 forums have received associate support for a wide range of reasons.

7.2 Learning and development

Webinars

We again invested in a webinar software package enabling us to deliver live workshops, allowing attendance to training sessions across all regions virtually. Parent carer forums value webinars as a resource as they can be uploaded to the internet and revisited at times to suit them, or when the issues are pertinent they can be utilised as a refresher.

We held a total of 7 webinars across a range of topics enabling expert presenters to deliver training information to a live audience.
Feedback from this training event included:

“After the webinar I did email a question to Steve whom replied the same day”

“Because it was so informative I will watch it again when it is uploaded”

“I enjoy webinars more than attending as sometimes when you are in a training room it goes off the topic and loses focus”

“Thank you for the opportunity to learn so much in 2 hours”

“I feel so much more empowered with facts and where to look if unsure”

“Webinars are great for those forums that are unable to access national and regional events”

**Face to Face learning**

We delivered two key training packages aimed specifically at parent carer forums. Leadership & Development courses were run in 4 regions to equip those who are officers within forums with the skills for effective leadership and management of their forums. Topics included governance, planning, decision-making, networking, facilitation, managing challenges, and meeting management. This 2 day course was delivered to a total of 50 attendees.

Feedback from this training events included:

“Fantastic. Brilliant discussion, comprehensive, enjoyable. Time flew”

“All future chairs/vice-chairs should go on this. Leadership part 2! All training vaulable. Plenty more networking opportunities.”

<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
<th>Registered</th>
<th>Attended</th>
<th>Views of recording</th>
</tr>
</thead>
<tbody>
<tr>
<td>21/05/2014</td>
<td>Participation and Health - Next Steps starts</td>
<td>28</td>
<td>17</td>
<td>8</td>
</tr>
<tr>
<td>20/08/2014</td>
<td>Improving health services for Disabled children</td>
<td>111</td>
<td>56</td>
<td>44</td>
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<tr>
<td>23/01/15</td>
<td>Using the law to challenge cuts to short break services</td>
<td>79</td>
<td>49</td>
<td>173</td>
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<tr>
<td>24/02/15</td>
<td>“I need to know!” SEND Reforms Afternoon session</td>
<td>85</td>
<td>33</td>
<td>40</td>
</tr>
<tr>
<td>24/02/15</td>
<td>“I need to know!” SEND Reforms Evening session</td>
<td>81</td>
<td>47</td>
<td>As above</td>
</tr>
</tbody>
</table>
Excellent delivery - tutors worked really well together. Kept on track and steered people if they needed to be ‘contained’ (in a great manner). More training: Leadership part, any training which will be appropriate. Trainers were fantastic!

Training was excellent and really useful, any more training is always valuable to steering group members.

Highly skilled and very talented trainers with huge amounts of experience/expertise. An inspirational day - thank you so much!

Feedback included;

"We will have a much better understanding of what part of the process we are working"

"Interesting and thought-provoking"

"Very relaxed and informative"

"An eye opener to me and I would now like to get myself involved in volunteering."

"All forums should attend on regular basis, even as a refresher or reminder."

For more information about this training, go to www.cafamily.org.uk/PCP/learning

Future face to face learning

Any future face to face learning will be dependent on forums’ using their grant funding for training as due to the reduction in the contract for the coming year, we will not have any capacity for face to face learning and development. We will, however, encourage forums to apply in clusters and to work with their regions and neighbours to pool resources so that they receive cost effective training and enhanced networking opportunities. Overall the feedback from the training taken place so far has been very good. Please see the below chart.
Co-production training
Following on from the success of the last co-production DVD and workshops, we agreed to work with the pathfinder champions, Mott MacDonald, the NNPCF, the Department and NHS England to develop a follow up which would explore the details about how to co-produce.

A series of six one day workshops on active co-production to enable parent carer forums, local authority representatives and health bodies to increase their knowledge and understanding of co-productive working, consider any barriers and how to overcome them, and to go away equipped with the tools and confidence to aid them in their future work together was planned and have since been delivered. We had a total of 236 attendees.

To accompany the workshops we developed a short film which includes a clip of the Minister reiterating the need for local authorities and health to work in partnership with families. The film can be viewed here

Feedback included;

“The positive impact that adopting co-production has had on the way the LA, PF, professionals work together and the outcomes achieved. Good start but we need to keep going in order to achieve continued good outcomes.”

“I feel more confident about being involved in co-production”

“Very useful, hope we will have more sessions in the future.”

“Parents / carers / young people & children are at the heart of decision making”

“Co-production is not an approach it’s a belief”

“Although our forum and LA could and should do more I feel we are well on the way to achieving good and effective co-production.”

“Inspired to make real changes to our working”

“Great to be with like-minded and passionate people. Sure things will improve - things won’t get worse for families!”

CO-PRODUCTION TRAINING FEEDBACK

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<thead>
<tr>
<th></th>
<th>Poor</th>
<th>Satisfactory</th>
<th>Good</th>
<th>Excellent</th>
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</thead>
<tbody>
<tr>
<td>Joining instructions, directions, etc</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Achievement of stated objectives</td>
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<tr>
<td>Value of training in relation to your forum</td>
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<tr>
<td>Quality of training and methods used</td>
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<tr>
<td>Responsiveness to participants</td>
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<tr>
<td>Stimulation of new ideas</td>
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<td></td>
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<tr>
<td>Improvement in skills/knowledge</td>
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<tr>
<td>Overall I would rate this course as</td>
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</table>
“Improved understanding of co-production / importance of co-production in achieving good outcomes. How to achieve co-production.”

7.3 National Event

The National Event and NNPCF AGM took place on 1st October 2014, with a record 124 parent carer forum attendees. Key note speakers included: Ann Gross, DfE Director of Special Needs and Children’s Services Strategy, and renowned barrister Steve Broach of Monckton Chambers. The day revolved around sharing of creative practice, particularly in relation to implementation of the Children and Families Act and the Care Act with other forum members, national updates, the second Annual General Meeting (AGM) of the National Network of Parent Carer Forums (NNPCF) and opportunities for networking for attendees.

Feedback included:

“Excellent talk from Steve on the Care Act - really enjoyed and very informative”

“Good examples of strategies to increase membership of forum and encourage participation”

“Great ideas from other forums. More info about the Care Act.”

“Inspiring how other forums have engaged parents”

“Amazing being with like-minded people”

“I just love being with so many other parent carers. The shared purpose is thrilling.”

“Some really good examples of coproduction. That parent participation is really valued. Things are working well in our area.”

“The brilliant presentations from the 4 forums - felt the power of what we do”

**NATIONAL EVENT FEEDBACK**

![Chart showing feedback scores for various aspects of the event, such as joining instructions, achievement of stated objectives, value of training in relation to your work, quality of training and methods used, responsiveness to participants, stimulation of new ideas, improvement in skills/knowledge, and overall rating.]
7.4 parent carer forums survey - Impact of the SEND Reforms

We have undertaken 4 SEND Reforms surveys with parent carer forums to coincide with those being sent to local authorities to review the implementation of the reforms. The information provided by both parties is triangulated and helps to inform the support offer to each local area.

Separate reports have been completed detailing the responses for each survey and these have been provided to the Department with a regional anonymous version made available publicly.

7.5 Strategic partnerships

We have continued to be involved in attending the SEND Advisory Group and the delivery partner meetings working with Early Support, National Parent Partnership Service, Preparing for Adulthood, Council for Disabled Children and Mott McDonald. Our regional advisors are members of the regional telekit and support the regional offer.

Early Support also asked us to deliver the parent carer information workshops to support individual parents to understand the SEND reforms. We developed the workshops with Early Support and the NNPCF called “I need to know” and identified with partners the areas where these workshops would be targeted.

The project period ran from September 2014 to February 2015. During this period

- 25 daytime events (10am – 2pm) held between 24th November and 5th February
- Sessions held in each region
- 2 webinars (one afternoon and one evening – 60 minutes each) on 24th February
- 750 available places at 25 events (30 per event)
- 634 actual bookings in total
- 536 actual attendees in total
- 85% of the 750 places were booked
- 85% of the 634 parent carers who booked actually attended
- 80 attended the webinar sessions
- The Contact a Family Facebook posts regarding the events reached 68,796 people with 238 people actively engaging with the posts via likes, shares and comments.
- 91% of parent carers who attended the session and completed an evaluation form said they agreed or strongly agreed that they would know where to get more help and assistance in relation to the SEND reforms
- 89% of parent carers who attended and completed an evaluation form said they agreed or strongly agreed that they felt better informed about how to get the support they needed
- 80% of parent carers who attended and completed an evaluation form said they agreed or strongly agreed that they felt more confident after the session
- 70% of parent carers who attended and completed an evaluation form said they agreed or strongly agreed that they felt isolated
7.6 Joint Bulletins

We continue to produce regular bulletins for forums with the NNPCF. The bulletins have been very successful with many forums telling us it is often the only communication they read as it provides them with the information they need in the way that they need it.

7.7 National Link Group

The National Link Group has met termly and is co-chaired with a member of the NNPCF. Partners from the Voluntary and Community Sector (VCS) have been invited to meet together to share practice and experience in relation to participation. It has continued to provide a valuable opportunity to enable other VCS partners to hear about the development of participation and forums and to share their own organisation’s developments in relation to participation. It has enabled cross fertilization of ideas and activities and provided a forum for shared learning.

7.8 Supporting the National Network of Parent Carer Forums

We continue to support the NNPCF through support to the Steering Group and employing a Programme Officer to support their activity. The NNPCF continue to strengthen and develop and provide their own annual independent report detailing their activity.
8 Conclusion

The last 12 months have continued to provide challenge for parent carer forums in England. The SEND Reforms, and opportunities to participate locally and nationally, have been significant. Some areas have embraced these opportunities and the culture change espoused within the Children and Families Act is being realised. In some areas this remains more challenging. The level of intensive associate involvement that some forums have required demonstrates challenges that forums have faced. Significant changes in stakeholder groups, partners, efficiencies and some cuts in service provision have placed greater challenges on some parent carers, and had an impact on forums.

However, what has also been demonstrated is the great achievements that many forums have attained, and the improved outcomes as a result of this. Parent carer participation is becoming more embedded, and where forums have strong and robust governance structures to assist them in times of challenge, they are able to ensure that participation does not become dependent upon individuals, but rather on the group.

The strengthening of parent carer participation and parent carer forums is reflected in the key principles of the Children and Families Act and the Code of Practice. Within this statutory guidance forums are recognised as the key partner for strategic participation. This clear and strong direction is warmly welcomed by forums, and further embeds and strengthens the strategic participation of parent carers in decisions and service provision for disabled children and children with special educational needs and their families.

The National Network of Parent Carer Forums has also been able to ensure that the voice of parent carers is embedded in national developments and achievements. It is clear that the participation of parent carers is more vital than ever because of the significant changes and transformation of services and legislation that underpin the support for children with special educational needs and disabilities.

Strong outcomes evidenced across England continue to demonstrate the efficacy and benefits of parent carer participation and provide the data to show the improvement to services that is achieved when there is effective parent carer participation or co-production.

The immense commitment and support shown by many parent carers across England who are active members of their forums, or involved in feeding in their views, is having a significant impact. These outstanding efforts are making a real difference, supporting service providers and commissioners to ensure that provision for disabled children and families are the best they can be, which ultimately promotes the wellbeing and life opportunities of disabled children and young people.

The final word has to be a huge thank you to all of the parent carers who have been part of their forum’s work.
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 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).