Strengthening the parent carer participation movement

An annual report through the experiences of parent carer forums 2015/16
Contact a Family provides advice, information and support to all UK families with disabled children, regardless of their disability, special educational need 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.

Under contract from the Department for Education, we support the development of parent carer forums across England, where parent carers work with service providers to improve how services are delivered in their local area. To do this we work in partnership with the National Network of Parent Carer Forums (NNPCF).

www.cafamily.org.uk

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 in receipt of the Department for Education parent participation grant. 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 that parent carers are able to have a voice and work as partners to develop and inform services, strategies and legislation concerning disabled children, young people and their families locally, regionally, and nationally.

www.nnpcf.org.uk

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Executive Summary

It gives Contact a Family great pleasure to present this report on the strength of the parent carer participation movement in England in 2015/16. It is compiled from the information parent carer forums submit as part of the DfE parent carer participation grant process and our unique perspective as the provider of the grants administration and support service to Parent Carer Forums in all local authority areas in England, on behalf of the Department for Education.

The information presented here is derived from two sources: the first is the monitoring information that Parent Carer Forums provide when accounting for the spend of their grant, which in this report covers their activity in 2014/15; the second is information on the nature and composition of forums, taken from their grant applications for the year 2015/16. At the top of each section of this report we clearly indicate which source has been used.

Drawing information from two different financial years presents some challenges for the conclusions we should draw, especially given the pivotal nature of the years in question, the first covering the introduction of the SEND reforms and the second, the beginnings of their implementation. We have been careful to include caveats around our findings throughout.

That said, all the information collated here was supplied within a narrow ‘real time’ window of just a few months, even though it falls across two reporting years: the monitoring data for 14/15 was gathered early in 15/16 and the application data for 15/16 in the following weeks. Therefore, we can combine both data sets into a good snapshot of the environment for parent carer forums at a particular point in time, that being early in the 15/16 financial year.

What will this report tell us?
The report presents a healthy, if emerging picture of the activity of forums in developing their pivotal role in the implementation of the reforms, and in mainstreaming the notion of co-production in local partnership working. Parent Carer Forums are in receipt of a grant in 150 of 152 local areas, enabling us to draw some broad conclusions about the overall national picture. Within the report we cover Parent Carer Forums’ composition, finance, and the environment in which they are working, as well as gaining some insight into their key outcomes, achievements and challenges.

Forum development and governance
We are greatly encouraged at the growth in numbers of parents in contact with their Parent Carer Forum and in those actively engaging in their work. Our data suggests that Parent Carer Forums are becoming well-established players within the local environment, and are developing their networks and influence functions well. However, one key challenge involves those parent carers in active steering group roles.
Here, numbers remain static and, anecdotally, we hear many stories of burnout amongst the most committed parent carers, who shoulder the bulk of their Parent Carer Forums’ representative and administrative duties. Recruitment and retention of parent carers in steering group roles appears to be a key risk, especially as demand for Parent Carer Forums engagement continues to increase.

Governance structures are evolving in response to this increased demand, complemented nationally by the progress that the National Network of Parent Carer Forums (NNPCF) made in 15/16 in developing their national voice and representative functions, which led to a visibly increased presence for parent carer participation across Westminster and Whitehall.

Finance and sustainability

Many Parent Carer Forums (55%) are finding ways to supplement their core DfE grant income and some take on additional functions locally. In this period, over half of all Parent Carer Forums generated or received additional revenue on top of their core grant, collectively generating £1.34m (around 60% of the value of the annual investment the DfE makes to all Parent Carer Forums). The majority of this additional income came from local authorities. Half of all Parent Carer Forums also reported receiving in-kind support from local partners, including contributions to meeting space and office costs.

Notably, however, the number of Parent Carer Forums receiving additional financial support to cover the costs of their representatives sitting on local partnership boards fell by 43% between 14/15 and 15/16 (from 42 to 24). The numbers reporting having a paid member of staff also fell by 18% in this period (from 49 to 40). Of course, we should not forget that many Parent Carer Forums (45%) receive no additional funding or support at all. Stakeholders should therefore be conscious of this very mixed picture, which when taken with reports of high levels of burnout amongst the most engaged parent carers, combined with increased demand for Parent Carer Forum engagement generally, will need careful monitoring in the coming months and years with support where necessary to enable Parent Carer Forums to continue to function at the level demanded of them.

How well is co-production working?

Parent Carer Forums are asked to report on the extent to which they feel their role is embedded with local partners, responding subjectively according to their interpretation of the different levels on the ‘ladder of engagement’ – co-production, participation, consultation or information. In 2014/15 Parent Carer Forums reported that their ‘co-production’ role fell by an average of 8% across education, health and social care, compared to the previous year. Levels to which Parent Carer Forums saw themselves as ‘participating’ presented a more mixed picture.

Though it is probably still too early in the life of the reforms to identify conclusive trends, further analysis of these subjective measures and qualitative evidence, when taken alongside the DfE SEND surveys, could prove instructive for practitioners supporting efforts on the ground.

That said, a key emerging picture is one of the capacity of Parent Carer Forums to engage. As one forum notes in section 6, as demand outstrips supply, forums could end up a ‘victim of their own success’. The key outcomes of co-production should be evident in the quality of the reforms’ implementation – by meaningfully engaging parent carers from the outset, a stronger voice for local families and better outcomes for those families should follow. This is the vision to which all Parent Carer Forums aspire.

Thanks and recognition

In 2016/17 Contact a Family is responding to these needs by evolving our support offer to Parent Carer Forums and the NNPCF in a number of key areas, including the development of regional working structures, better engagement of local health partners and supporting the next phase of the NNPCF’s development. We could not, of course, play such a role without the incredible efforts of our partners, also working tirelessly to embed this cultural change at local, regional and national levels. We are grateful for the continued support and engagement of the NNPCF, and of course the Department for Education and their other contracted partners, including Mott MacDonald, National Development Team for inclusion (NDTi) Preparing for Adulthood (PIA) and the Council for Disabled Children (CDC). We are also delighted to be developing our partnership with national health agencies, including NHS England, the Department of Health and many of the Royal Colleges.

Working closely with the NNPCF and the DfE, Contact a Family is extremely proud to have had the opportunity to support and nurture the development of parent carer participation since 2008. As a charity, participation is in our DNA – we were formed nearly 40 years ago by parents who knew the value of their own experience and wanted to use it to help others experiencing similar challenges.

Our final word must therefore go to those parent carers themselves – the nearly 80,000 who are engaged with their Parent Carer Forums across England – to whom all stakeholders reading this owe a huge debt of gratitude for their time, commitment, passion and dedication. Without their efforts, the vision for the SEND reforms would have remained just that. The Parent Carer Participation movement will continue to develop, but is already both very powerful and extremely valuable and, with appropriate nurturing and investment, has an awful lot more still to contribute.

Gethyn Williams
Director of Development and Engagement

Gail Walshe
Head of Parent Carer Participation
1 An overview of Parent Carer Forums

1.2 Forums’ governance and legal status

- The number of Parent Carer Forums that were constituted groups remained fairly constant at 65 in 2015/16, slightly up from 62 in 2014/15.
- The number of Parent Carer Forums registered as charities increased, from 28 in 2014/15 to 38 in 2015/16.
- Those registered as Community Interest Groups fell from 4 in 2014/15 to 1 in 2015/16; conversely, only one Parent Carer Forum was a social enterprise in 2014/15 but four were in 2015/16.
- 23 Parent Carer Forums have no specified legal status, identical to 2014/15.

1.3 Levels of parent carer involvement in Parent Carer Forums

<table>
<thead>
<tr>
<th></th>
<th>2014/15</th>
<th>2015/16</th>
<th>% Change</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total reach:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Carers</td>
<td>67,191</td>
<td>77,678</td>
<td>+16%</td>
</tr>
<tr>
<td><strong>Total engagement:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Carers</td>
<td>34,367</td>
<td>36,452</td>
<td>+6%</td>
</tr>
<tr>
<td><strong>Leadership:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Carers</td>
<td>1,386</td>
<td>1,341</td>
<td>-3%</td>
</tr>
</tbody>
</table>

- In 2014/15, the number of parent carers for whom Parent Carer Forums had contact details totalled 67,191. In 2015/16 this rose by 16% to 77,678.
An increase in the numbers of parent carers actively feeding their experiences into the work of Parent Carer Forums was also reported – up 6% to 36,452. Thus, overall in 2015/16 we saw an increase in the breadth and depth of parent carer engagement in forums.

However, the number of parent carers on management or steering groups involved in running Parent Carer Forums showed a small decline compared with the previous year.

1.5 Overview of additional income and in kind support

- In 2015/16 there was an increase in the number of Parent Carer Forums receiving funding from their local authority (excluding additional funding for service delivery) – 69 compared with 59 in 2014/15.
- A small number of Parent Carer Forums also received funding from health partners (up from 2 in 2014/15 to 6 in 2015/16).
- However, the number of different organisations providing additional funding to Parent Carer Forums in 2015/16 (i.e. beyond local statutory partners) has declined. In 2014/15, there were eight providing additional funding and a further six providing funding in conjunction with the local authority. In 2015/16, this declined to five and three respectively.

The number of areas where a participation worker is employed reduced to 40 in 2015/16, from 49 the previous year.

- In 2014/15, 42 Parent Carer Forums said that their local authority or health provider made payments to parent carers who sit on strategic decision-making boards or committees. This dropped significantly to 24 areas in 2015/16.
- The numbers of Parent Carer Forums that reported receiving support in kind (such as photocopying and the use of meeting rooms) fell slightly from 75 areas in 2014/15, to 72 in 2015/16.
2 Composition of Parent Carer Forums

Analysis of 2014/15 monitoring forms

The data in this section draws on responses from 145 Parent Carer Forums' grant monitoring forms, though not every form was fully completed, nor every question relevant to every Parent Carer Forums, so the total in each graph or table is not necessarily n=145.

2.1 Steering group, representation and membership

- In 2014/15 there was no significant change in the numbers of members involved with their Parent Carer Forum at a steering group level (a total of 1,431).
- The most common size of a steering group was between 6 and 10 members, though this was slightly down on 2013/14 ( whilst the 11–15 category grew by a comparable amount).
- A similar picture was witnessed amongst the numbers of steering group members engaged in task groups, reflecting the close link between being a member of a steering group and having an active role in the work of the Parent Carer Forums (for many, steering group membership is about more than just governance).
Profile of steering group 15/16 with 16-20 members

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

Comparison year on year

- **2015/16**
  - 1-5: 2%
  - 6-10: 6%
  - 11-15: 3%
  - 16-20: 2%
  - 21-25: 3%
  - 26-30: 2%
  - 30+: 3%

- **2014/15**
  - 1-5: 2%
  - 6-10: 6%
  - 11-15: 3%
  - 16-20: 2%
  - 21-25: 3%
  - 26-30: 2%
  - 30+: 3%

**2.2 Diversity in Parent Carer Forum membership**

- There was a steady increase in the number of Parent Carer Forums collecting diversity information about their members, up from 49% in 2013/14 to 54% in 2014/15.

**2.3 Annual record of membership**

- There was no significant difference between 2013/14 and 2014/15 in the numbers of Parent Carer Forums keeping records of demographic details of their membership and steering group. Almost all Parent Carer Forums do this to support their commitment to diversity and equality of representation.

**2.4 Impairment type**

- Parent Carer Forums were asked if there was an impairment type represented by a significantly greater number of their members. This has increased slightly, with 69% saying yes in 2013/14 and 73% in 2014/15. Of those who said that an impairment type predominated, all except four said that this was Autistic Spectrum Condition.

**2.5 Links with other groups**

- Parent Carer Forums were asked if they send information, and link with other groups of parent carers and organisations that support disabled children in their area. In both 2013/14 and 2014/15 the vast majority said yes.
3 The environment for co-production

Analysis of 2014/15 monitoring forms

In their grant monitoring, forums provide their subjective views on the extent to which they feel engaged in local partnership working – in the key reform areas of education, health and social care, but also in specific initiatives such as the development of the Local Offer or Short Breaks Statement.

In providing these views, Parent Carer Forums were asked to pick from the categories of engagement used in the ladder of participation.

3.1 How engaged Parent Carer Forums feel in education, health and social care

As noted in the Executive Summary, whilst headline levels of co-production and participation appear to be down in most areas compared to 2013–14, we should be mindful of the reporting year being the first year of the SEND reforms implementation, and not necessarily judge this as a trend although further analysis into the reasons behind what the figures may be suggesting would enable us to gain a clearer understanding. Readers should remember these are subjective views and snapshots taken at particular points in time.

<table>
<thead>
<tr>
<th>Level of engagement</th>
<th>Year</th>
<th>Education</th>
<th>Health</th>
<th>Social Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Co-production</td>
<td>2013/14</td>
<td>57%</td>
<td>24%</td>
<td>40%</td>
</tr>
<tr>
<td></td>
<td>2014/15</td>
<td>45% (-12%)</td>
<td>18% (-6%)</td>
<td>34% (-6%)</td>
</tr>
<tr>
<td>Participation</td>
<td>2013/14</td>
<td>25%</td>
<td>36%</td>
<td>34%</td>
</tr>
<tr>
<td></td>
<td>2014/15</td>
<td>35% (+10%)</td>
<td>33% (-3%)</td>
<td>27% (-7%)</td>
</tr>
<tr>
<td>Consultation</td>
<td>2013/14</td>
<td>9%</td>
<td>15%</td>
<td>12%</td>
</tr>
<tr>
<td></td>
<td>2014/15</td>
<td>10% (+1%)</td>
<td>28% (+13%)</td>
<td>17% (+5%)</td>
</tr>
<tr>
<td>Information</td>
<td>2013/14</td>
<td>3%</td>
<td>13%</td>
<td>6%</td>
</tr>
<tr>
<td></td>
<td>2014/15</td>
<td>6% (+3%)</td>
<td>10% (-3%)</td>
<td>10% (+4%)</td>
</tr>
</tbody>
</table>

3.2 Engagement with Short Breaks Services Statement

There was a reduction in the number of Parent Carer Forums telling us they had co-produced the Short Breaks Statement with their local authority (down from 46 in 13/14, to 28 in 14/15). Levels of self-reported participation also showed a decrease in this period, from 26 to 16.

‘Not surprisingly given the trend noted above there was a significant increase in areas that said they were only consulted about the statement (up from 23 in 2013/14 to 34 in 2014/15). In addition, 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 (up from 15 to 28 in 14/15). These findings could suggest cause for concern, but further qualitative research is probably needed to understand the underlying reasons behind them.’

3.3 Involvement with the Local Offer

The extent to which Parent Carer Forums have been involved with developing their area’s Local Offer appears to have diminished in 14/15 – 57 forums compared with 75 in 13/14. This possibly reflects the completion of the development stage, and subsequent move to implementation in many areas. The modest increase in numbers of forums ‘actively participating’ (48 to 52) may support this assumption.
3.4 Regional network meetings

Parent Carer Forums have the opportunity to meet at least once a term with other Parent Carer Forums in their region. This is a chance for them to share experiences, hear updates from their NNPCF regional representative and Contact a Family Parent Carer Participation Adviser, and to feed back their views.

There has been an increase in the number of Parent Carer Forums able to attend these meetings, from 79% in 2013/14, to 86% in 2014/15. The rise in the perceived value of regional engagement is a key area of our capacity-building support in 2016/17, as well as an important focus for the work of the NNPCF.

4 Outcomes of parent carer participation

Analysis of 2014/15 monitoring forms

The headline outcomes reported by Parent Carer Forums in this period include observations that they are growing in size and influence, with key roles to play in facilitating parent consultations and representation on key decision-making boards. In many areas the concept of co-production and legitimate roles of the Parent Carer Forums in championing this appear to be well-embedded, with positive outcomes reported for parents and service providers and in securing changes that improve lives locally for parent carers and their families (for example in service delivery and policy around the roll out of EHC Plans, personal budgets, Local Offer). As one Parent Carer Forums below summarises:

"Parents reported feeling more empowered, whilst professionals reported being able to empathise with parents and alleviate anxiety and anguish over children's development."
Below we summarise an example of a key outcome from one forum in each region, from work undertaken in 14/15.

4.1 From the North West
- Parent carer views have been used to help review, shape and develop the Local Offer website, a new speech, language and communication service, a new CAMHS Tier 2 service and a new community paediatrics service.
- Parents’ views and experiences have been at the heart of the service specifications showing parents that their views matter and ensuring that the services commissioned meet the needs of the people using them.

4.2 From the East of England
**Outcome 1: Increased awareness of the forum and the ethos of co-production**
- The forum has become better known by all as a way to improve SEND provision.
- A larger proportion of the LA and Health colleagues now recognise the duty and benefits of including the forum and parent carers in strategic decisions.
- Parent carers are beginning to feel that their voice is being heard and that they can make a difference to local services.

**Outcome 2: Services being co-produced with the families that access them.**
- More parent carers are involved in influencing the services they access. Parent carers are influencing implementation of the new legislation surrounding them by their strategic involvement within all of the SEND work streams.

4.3 From London
- We have delivered an extensive programme of consultation events particularly focusing on health, transition and the SEN changes (including the Local Offer and EHCPs) and fed back to statutory partners through the Parent Reference Group.
- We have been very productive in feeding back parent carer views; however, in 2015/16 we need to focus on ensuring that feedback translates into policy and commissioning changes.

4.4 From the East Midlands
- We held a series of three SEND workshops for parents and professionals. This provided a chance to participate in learning more about the new SEND reforms.
- Parents reported feeling more empowered, whilst professionals reported being able to empathise with parents and alleviate anxiety over children’s development.
- The report of our workshops was circulated to the LA, services providers and parents and published online, helping to inform parent carers unable to attend.
- The report is also evidentially helpful - parents are able to see how participation gave them a better outcome, having come away fully informed about local implementation of the reforms. For the LA, it gave them a better insight to hear first-hand parents’ anxieties and thoughts on the reforms.

4.5 From the North East
- Last year the LA circulated a request to share database information to enable the parent forum to access contact details to be able to share information and events. This database holds approximately 450 parent carer contact details.
- Of these only 20 did not wish to receive information, and as a result our database grew from 78 to 430. Our new Facebook page also has 139 contacts.

4.6 From the South East
- We have been given considerable opportunity to co-produce the SEND reforms, requiring us to dedicate a greater amount of time than originally planned.
- The results are an EHC Plan and related paperwork that are more family friendly, a developing Local Offer and a Personal Budget policy that commits the county to review block contracts and provide opportunities for flexibility in the future.

4.7 From the South West
- Being invited by the director of children’s services to lead and chair the SEND Participation and Engagement Group, as recognition of the work we do with the Children’s Trust Board. We are at present active members of 33 Boards/groups across Children’s and Health Services.
We also asked Parent Carer Forums to tell us what their greatest achievements were over the year. Below are examples from each of the regions. All Parent Carer forums expressed their pride in their role in representing parent views in the roll out of the SEND reforms and monitoring their implementation; they value the links they have built with local health partners and with harder to reach communities; establishing trust with local partners; formalising their partnership working with the local authority; and, internally making good progress in developing their governance arrangements, whilst boosting their patience and resilience through their experiences.

“We have built positive relationships with the LA which has led to excellent outcomes regarding the SEND reforms and the EHC Plans.”

4.8 From the West Midlands
- Our reference group meets every 6 weeks, sharing information with lead officers from the LA, Health and Social Care, identifying training or support needs for forum members, and is available for co-productions and consultation.
- Our members also sit on a variety of external strategic bodies and are involved in planning of consultations and events; we ran twilight sessions on the SEN transport consultation which enabled us to ensure working parents reliant on travel assistance could have a voice regarding the proposed changes to policy.

4.9 From Yorkshire and Humber
- Membership has increased by 100+. We involve parents by running a range of smaller groups and larger consultation events. Some parents are uncomfortable in big groups and don’t feel confident to express their views so smaller events in local areas were arranged accordingly.
- This has enabled us to gather views across a larger number of parents to enhance participation activities with Education, Health and Social Care and enable parents’ voices to influence service design and delivery - for example the improvements to the local CAMHS service, parents’ input (ongoing) into preparing for adulthood and the Local Offer.

5 Achievements of Parent Carer Forums

Analysis of 2014/15 monitoring forms
We also asked Parent Carer Forums to tell us what their greatest achievements were over the year. Below are examples from each of the regions. All Parent Carer forums expressed their pride in their role in representing parent views in the roll out of the SEND reforms and monitoring their implementation; they value the links they have built with local health partners and with harder to reach communities; establishing trust with local partners; formalising their partnership working with the local authority; and, internally making good progress in developing their governance arrangements, whilst boosting their patience and resilience through their experiences.

“We have built positive relationships with the LA which has led to excellent outcomes regarding the SEND reforms and the EHC Plans.”
5.1 **From the East of England**
- We are proud of the work we have done on the SEND reforms, and representing parents’ views in this process. This continues as we monitor how well the reforms are implemented.
- We are really pleased to have developed stronger links with Health - the Clinical Commissioning Group in particular. We have been invited to join the CCG task & finish groups so that we can achieve real co-production of health services, and our first involvement will be the T&F group for ‘Complex Child’.

5.2 **From the North West**
- We have engaged with the local Council of Mosques and reaching seldom heard families, offering the SEND brochure and Forum leaflets in Urdu and offering translators, so families would feel comfortable to engage in a language of their choice.

5.3 **From the North East**
- We organised 5 locality events, attended by over 300 parent/carers and professionals to look at implications/issues related to the SEND reforms. Through this engagement we now have much better dialogue with the LA and with health professionals. It has been encouraging to receive feedback from both that they feel the forum is more approachable.

5.4 **From London**
- Building on nearly 30 years of representing parent carers’ views, and working closely with the Local Authority and local NHS, we have drafted and signed a partnership agreement between the forum and the LA. It confirms the forum is recognised by the LA, encompasses the ways we strive to co-work and explains the responsibilities of both parties.

5.5 **From Yorkshire and Humber**
- Our progress is typified by the way we learn from our mistakes and remain patient in pursuing co-production.

5.6 **From the East Midlands**
- Supported by the coordinator, the steering group were able to agree a mission statement and constitution that was accepted by the new management group of parents, ensuring the completion of a long-standing task and that parents feel a new enthusiasm as the group moves forwards to become financially independent, hoping to achieve charitable incorporated organisation status in 2015/16. This has been essential to creating a clear vision for our work.
- The new management group has strong leadership through two co-chairs, a treasurer and secretary, and four trustees. Decisions are made as a steering group with parents are feeling more empowered and in control.

5.7 **From the South West**
- We have built positive relationships with the LA, which has led to excellent outcomes regarding the SEND reforms and the EHC Plans. Parents have been involved in developing a Co-Production Charter that the directors of children’s & adults’ services and senior politicians have signed up to and agreed should be an underlying principle to all future work.

5.8 **From the South East**
- We have helped to prevent LA cuts to short breaks whilst maintaining good relationships.
- Our move to CIO (Charitable Incorporate Organisation) and development of a new strategy/direction has helped ensure sustainability.
- We have managed a smooth transfer to a new chair with constant support and advice, excellent communication and freedom to start moving to the next stage of our development without criticism or interference.

5.9 **From the West Midlands**
- The opportunity provided by the SEND reforms has enabled the LA relationship to grow and mature, with the positive experience of working in partnership we have established as a key strategic voice in the eyes of the council.
- Through working together we have learnt to trust each other and been able to have open and honest dialogue that has benefited everyone. The LA has been a key advocate of working in partnership with parent carers when discussing the SEND reforms with other partner organisations. The development of this relationship has enabled us both to work together on other areas of challenge, such as the lack of transparency around social care decision making.
6 Challenges for Parent Carer Forums

Analysis of 2014/15 monitoring forms
We also asked about the typical challenges Parent Carer Forums are facing. While for some there are still issues getting meaningful engagement with local statutory partners, the majority of responses focus on their capacity, particularly amongst steering group members, for representational roles and other forms of engagement. Demand for this work is outstripping supply, leading to Parent Carer Forums being thinly-stretched and in some cases, parents experiencing burnout. As one Parent Carer Forum puts it:

"The demand for participation has increased and the availability of [forum] reps has decreased….It seems our biggest success is now our biggest challenge."

6.1 From the East of England
- Getting the LA to acknowledge the issues for children and families around the way that the conversion process for EHCPs is being done.
- Coping with the level of demand for parent rep time placed on the forum.

6.2 From the North West
- Although we have had a large increase of members this year there are still not enough parents who are willing to be involved at a higher level. This means that representation demands are still falling on the same small number of parents, which can lead to them feel overwhelmed and burnt out. We have not had a presence on many of the strategic boards in the area purely as a result of this. Tackling this will be a goal for the coming year.

6.3 From the North East
- We had intended to run “pop-up” shops throughout the city but found the management of shopping centres unresponsive.
- Capacity of the steering group due to personal circumstances has been a challenge.
- Our database is not fit for purpose and needs to be replaced as does the website.

6.4 From London
- Unfortunately, the intensive nature of the implementation of the SEND reforms has been a major burden on the majority of the steering group members. We did not have time to really capitalise on the momentum we had worked towards in attracting new members. Without time to nurture, transfer skills and experiences, valuable knowledge is lost.
- What became clearer this year is the need for a pan-disability, parent-led support group. Addressing this need has hindered our ability to recruit parents to concentrate on participation. We are concerned that the continuing cuts in various support services and benefits will further burden the progress of the forum.

6.5 From Yorkshire and Humber
- Communication and involvement with the LA, Health and Social Care is a challenge.
- There is a lack of understanding of co-production within the LA at all levels.
- Capacity to meet the needs of the forum – e.g. travel expenses very high when reaching out to isolated parents.
6.6 From the East Midlands

- Sustainability – parent carers had to step back when their children’s health deteriorated. This left a few core members to cover a vast amount of work stream meetings as well as the administration of the group.

- On top of this was the workload of organising the Forums events. It seems our biggest success is now our biggest challenge – the demand for participation has increased and the availability of parent reps has decreased.

6.7 From the South West

- Managing an ever-increasing workload and increased pressure to meet deadlines, etc.

- An ever-growing demand for our services, face to face consultations, surveys and reported to effect change.

- Plan, organise and deliver events and consultations while still managing daily demands.

- Time is always the biggest issue. It can be difficult to find the time to respond to the daily volume of emails while balancing the need to be embedded in strategic meetings as part of everyday practice.

6.8 From the South East

- Enrolling, nurturing and sustaining a healthy parent rep population, including enrolling parents to the steering group

- Balancing parent participation and active support for the LA, actively trying to embed SEND reforms, joint working between professional agencies, having enough money to pay people to be actively engaged in our work - financial pressures mean that parents need to find work elsewhere.

6.9 From the West Midlands

- Whilst senior leadership teams from all partnerships are signed up to the involvement of parents in co-producing services, there has been some resistance from managers and frontline practitioners. Ongoing work will be done to reduce the resistance through the promotion of the forum’s success.
7 Contact a Family’s support offer

7.1 Our core offer to all Parent Carer Forums

All Parent Carer Forums continue to be able to access the core offer of support from Contact a Family. This includes a named Parent Carer Participation Adviser (PCPA), access to learning and development opportunities, regular communications, an annual event hosted jointly with the NNPCF, and the opportunity to engage with their regional network.

We have a team of Parent Carer Participation Advisers (PCPAs) whose role is to be the first point of contact for all Parent Carer Forums in their regions. They offer advice and support via telephone, email and in person. They also attend regional network or cluster meetings and support Parent Carer Forums with their grant applications and monitoring submissions. PCPAs can also offer support to Parent Carer Forums strategic partners, and in doing so raise the profile of participation, and the importance of co-production. Parent Carer Forums told us that this resource is highly valued.

From April 2015 to the end of March 2016, PCPAs provided many hours of this core support offer to Parent Carer Forums. Parent Carer Forums also accessed additional support via a suite of online resources, including a series of webinars (many of which are delivered in partnership with Parent Carer Forums to facilitate the sharing of good practice). Our grants team continues to administer the £15,000 DfE grant for all forums, an investment of £2.3m per annum.

7.2 Intensive support for Parent Carer Forums

Sustaining and developing parent carer participation can be extremely demanding. Much of it is reliant on the support of parent carer volunteers with (often) very challenging personal lives. Expectations from local and national partners and other parent carers put a lot of additional demands on these very dedicated but busy volunteers and this can inevitably lead to challenging situations for Parent Carer Forums from time to time. For these reasons, we retain a pool of highly-skilled associates who can provide additional support to forums, local authorities, health partners and other stakeholders with specific problems. In 2015/16, 36 forums accessed associate support for a wide range of reasons, equating to over 140 days of support.

7.3 Learning, development and networking for Parent Carer Forums

Annual National Parent Carer Forum Conference

Last year’s National Event and NNPCF AGM took place on 8 October 2015 in London, with a record breaking 165 parents from 87 parent carer forums in attendance. Our key note speaker was Ann Gross, DfE Director of Special Needs and Children’s Services Strategy. The day included sharing from Parent Carer Forums across England about their successes, and managing challenges; national updates on Contact a Family’s health & short breaks projects; the third Annual General Meeting (AGM) of the National Network of Parent Carer Forums (NNPCF) and networking opportunities for attendees. Feedback demonstrated how delegates valued the information provided, the opportunity to learn and network with other Parent Carer Forums and the size of the gathering as a key symbolic annual moment for parent carer participation.

Webinar learning series

Throughout 2015/16, we continued our investment in a webinar package which enables us to deliver live workshops, allowing virtual attendance at training sessions to Parent Carer Forums from all regions. 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 9 webinars across a range of capacity-building and thematic topics, chosen by Parent Carer Forums and delivered by in house experts. Parent Carer Forums innovating in key areas, and external partners. In this year our webinar programme reached over 700 individuals.

7.4 Facilitating the intelligence role of Parent Carer Forums

Working with the NNPCF

We have continued to work in partnership with the NNPCF steering group and to host them, to enable many of the practical aspects of their representative work to take place which helps free them up to represent the local and regional feedback from Parent Carer Forums at a national level. They receive funding from the DfE for a designated Programme Officer, employed by Contact a Family, to ensure their personal and strategic activity is supported.

In particular we continue to produce regular joint bulletins for Parent Carer Forums that share information on recent strategic involvement and opportunities to get involved with consultations, as well as sharing examples of good practice and success stories. The bulletins have been very successful, with many Parent Carer 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.

Working in partnership with the NNPCF steering group helps inform our work with all Parent Carer Forums and partners. It sometimes challenges our thinking but always enables us to make decisions, confident that parent carer views are informing our choices.
7.5 SEND surveys

In 2015/16 we ran two SEND reforms surveys for Parent Carer Forums (in June and November 2015) mirroring those the DfE send to local authorities to review progress in the implementation of the reforms. The information provided by local authorities and Parent Carer Forums is triangulated and helps to inform the support offer to each local area. Full reports are provided separately to the DfE, with an anonymised regional feedback summary version made available publicly.

7.6 Wider strategic partnerships

Contact a Family is one a number of organisations delivering strategic intelligence and operational support to local partners engaged in the SEND reforms, under contract with the Department for Education. We continue to engage with our partners to ensure that the contribution of parent carer participation is properly understood and that parent carers are engaged in local, regional and national work, wherever appropriate.

In 2015/16 we also ran two additional but related projects to further parent carer participation, under grant from the Department for Education. One was the coordination of the Short Breaks Partnership, whose members also included Action for Children, KIDS and the Council for Disabled Children. The other focused on increasing the ability of Parent Carer Forums to successfully engage with local health partners, particularly clinical commissioning groups (CCGs).

7.7 Parent Carer Forum feedback

As you would expect, Contact a Family regularly asks Parent Carer Forums to what extent they feel our service is meeting their needs. In 2014/15 this is what they told us.
Below are a series of quotations from monitoring forms demonstrating what Parent Carer Forums most value about our service:

“...We have received some fantastic support from CaF through both the regional adviser and the associate support, which has helped us to negotiate some difficult situations over the last year.”

“The forum looks forward to receiving the regular newsletters and bulletins as they have always been interesting and informative. The forum also found the CaF website to be most useful and the webinars very helpful.”

“CaF provided a vital role in working with parents to re-establish a parent carer forum in [our area] through a series of workshops and meetings, providing templates of policies etc. and advice by telephone.”

“...Truly great and very personalised support! The guidance and continuous encouragement from the CaF adviser had been exceptional and inspired us [forum] to approach our local council with request for further funds. The CaF adviser suggested ideas and gave examples from other forums of how to best approach the council and what arguments may be useful in negotiating additional funding and forum needs. This had led to additional funding being agreed and creation of a new, exiting role for the [forum] – a parent forum development worker (starting in April 2015)”

“There has never been a moment that we felt unsupported or not understood, on the contrary – our anxieties and worries were met with positive guidance and had led to doubling the amount of forum steering group members and creating an employment opportunity for a parent.”

“Before contacting the parent forum for information please check within your organisation if the information has already been sent to a colleague.”

“At regional meetings we hear about what is happening nationally, and are often given tasks that the national NNPCF & CaF teams would like us to do. However, these tasks (mainly around the SEND reforms) have often been done locally already, leaving us with a duplication of effort. This can mean that a region’s own issues do not get as much attention as the national ones, nor do we know whether our issues reach the national team or necessarily receive a response back.”

And finally, we ask forums for their suggestions on what more we could provide. Here’s what they told us in 14/15:

“Grant time scale needs looking at. Effectively we only have 10 months a year to organise activities and spend the grant. More opportunities for the regional adviser and NNPCF rep to attend forum and or other events in the region.”

“As a suggestion perhaps pick one region at a time to champion their work nationally – This would push up standards across the board and keep all forums striving to do better for their families.”

“It would be beneficial if webinars were presented more than once ‘live’ at different times of day to suit all parent carers and if they were uploaded immediately to the website, rather than weeks later as quite often happens, as the forum feel these are really useful resources and would like to be able to access them immediately!”

“When discussing this monitoring form at our steering group many people commented that they didn’t know and had never met a CaF adviser and didn’t know the team at all. Whilst we were delighted to have the director come to a conference as keynote speaker a while ago, members did report it would be really good to have some proactive direct contact even with those forums deemed to be ‘doing ok’ or perhaps some visits out to the forums who have not had one in previous contracts.”

“We recognise that they are very stretched but would very much like more 1:1 support and guidance, particularly in developing our steering group and building a sustainable forum.”

We also ask for and listen to constructive feedback on how we can improve our service. Here’s what some Parent Carer Forums told us in 14/15:

“It would be nice for the regional adviser to visit all forums and not just when things go wrong.”

“It would be good in the future to receive more notice of meetings and workshops, as we work part-time and term time only. The [forum] calendar is planned a term in advance so it can be difficult accommodating meetings at short notice.”

“As the new chair and new to the PCF world, perhaps a bit more hand holding and direct guidance might have been useful. Although having said that I do know CaF are there and would have rung if necessary.”
To discuss any aspect of the report please contact Gail Walshe, Head of Parent Carer Participation 01296 713 138, gail.walshe@cafamily.org.uk

**Contact the media office**
If you have a press enquiry about Contact a Family’s work, or for spokespeople or to speak about family case studies, contact our press office on 020 7608 8741 or email press@cafamily.org.uk.

We also operate an out of hours and weekend service on 0759 993 0090.

**Contact the regional parent carer participation team**
Carolyn Deveney, Operations Lead (North West, Yorkshire and Humber, East and West Midlands) 07905 917 066, carolyn.deveney@cafamily.org.uk

Sarah Lee, Operations Lead (North East, London, South East, South West and East of England) and Regional Adviser (North East) 01289 387089, sarah.lee@cafamily.org.uk

Catherine Wood, Regional Adviser (East Midlands, West Midlands) 01484 861688/07920 654960, catherine.wood@cafamily.org.uk

Heather Tarbuck, Regional Adviser (London North East, London South) 020 7326 4522/07920 655165, heather.tarbuck@cafamily.org.uk

Julie Singleton, Regional Adviser (South East, East of England, Southwark) 07910 795 960, julie.singleton@cafamily.org.uk

Sue Mennear, Regional Adviser (South West, Berkshire) 0117 9512 387, sue.mennear@cafamily.org.uk

Laura Burling, Regional Adviser (Yorkshire & Humber, 8 North West**, Worcestershire) 01625 537 342, laura.burling@cafamily.org.uk

Miranda Parrott, Regional Adviser (North West London) 07539 540461, miranda.parrott@cafamily.org.uk

Kate Hurn, Regional Adviser (North West) 07458 045694 kate.hurn@cafamily.org.uk

**Contact the NNPCF**
Please feel free to email the National Network of Parent Carer Forums (NNPCF) at info@nnpcf.org.uk or contact Sarah Gallimore, Programme Officer by email at sarah.gallimore@cafamily.org.uk, or by telephone 020 7608 8708.

**Contact a Family**
For information and advice on any aspect of caring for a disabled child, parents can contact our helpline by freephone, email, Facebook or Twitter.

Freephone: 0808 808 3555
(9.30am–5pm, Monday-Friday)

✉️ helpline@cafamily.org.uk
👩‍💻 facebook.com/contactafamily
🐦 twitter.com/contactafamily
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 advisers. 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).