How is Parent Carer Participation working across England?
We are Contact, the charity for families with disabled children. We support families with the best possible guidance and information. We bring families together to support each other. And we help families to campaign, volunteer and fundraise to improve life for themselves and others.

Under contract from the Department for Education we support the development and sustainability of a Parent Carer Forum in almost every local authority area in England, through the administration of grant funding and support and advice from a named Participation Advisor. Parent Carer Forums work strategically with statutory partners to improve service delivery and outcomes for families with disabled children in their local area. To support this, Contact works in close partnership with the National Network of Parent Carer Forums (NNPCF) and other strategic reform partners of the DfE.

www.contact.org.uk
Parent Carer Participation in 2016-17

Reach is increasing...
82,000 parent carers are now connected to 150 Parent Carer Forums across England. Membership is up 29% since 2012-13.

Finance and sustainability
55% of Forums receive some additional income, but 45% still operate on the DfE grant alone. These proportions have remained similar since 2012.

Stronger governance
In 2016-17, 95% of DfE grants were held by parent carer-led organisations.

But engagement is more challenging
However, levels of member engagement remain static, and the numbers of those engaged in leadership roles is decreasing.

This suggests the work of representation and running Forums is falling on fewer shoulders (proportionately) every year.

The environment for co-production
Since 2011-12 we have asked Forums to what extent they feel they co-produce with local statutory colleagues in Education, Health and Social Care.

Rates of co-production with education partners peaked in 2013-14. Forums’ increasing understanding of co-production may be one factor behind the fall in rates since, as local relationships are judged by increasingly higher standards.

Though starting from a lower baseline, rates of co-production with health partners now appear to be showing an upward trend.

And although rates of co-production with social care partners show little material change over time, the decline since 2013-14 is taking place alongside a corresponding downward trend in participation, as our full report demonstrates.
EXECUTIVE SUMMARY

It gives us great pleasure to present this report on the strength and health of parent participation in England in 2016-17. It is compiled from the information Parent Carer Forums submit as part of the DfE-funded small grants scheme, which Contact has administered since 2008. The intelligence and information used here is derived from two sources – the monitoring Forums provide when accounting for their grant (covering activity in 2015-16) and their grant applications (for 2016-17). Drawing information across two years presents some challenges in presentation, but with care we are able to offer a rich snapshot of the environment for Forums at a particular point in time.

WHAT DOES THIS REPORT TELL US?

Within we report on the large number of factors affecting the ability of Forums to champion and mainstream parent participation in their local areas. Inevitably this reflects a very mixed picture of success and challenge, but as Forums are in receipt of a grant in 150 local areas we are able to illustrate national trends (in England) and draw some broad conclusions. Our data covers Forums’ composition, reach, finance, governance and operating environment for participation.

Beyond this we take the opportunity to recognise some of their key outcomes, achievements and challenges. And because we place such high value on parent participation, we devote a significant chunk of this report (sections 4, 5 and 6) to the experiences of Forums as told in their own words.

REACH AND GOVERNANCE

We continue to be encouraged by the growth in Forum membership, now nearly 82,000, an increase of 29% since 2012-13. The proportion of those members taking an active part in the work of the Forum has dipped in recent years, but remains within a broad upward trend.

However, numbers of parent carers engaged in Forum leadership roles have continued to fall, adding further evidence to the view that the bulk of Forums’ work is undertaken by a committed civic core. When this is considered alongside an overall growth in membership, it could also be argued that pressures on Forum leaders are increasing proportionately.

FINANCE, RESOURCES AND SUSTAINABILITY

We continue to see a roughly equal split between those Forums generating income in addition to their core DfE grants (55% of Forums again this year) and those that operate on the grant alone. Of those that do generate additional income, the majority comes from local statutory partners – primarily the local authority, but increasingly local health partners in tandem with the authority.

Collectively this additional income amounts to £1.38m, a marginal increase on last year. Within this figure there is a tendency towards larger sums for smaller numbers of Forums, suggesting those with strong financial relationships are becoming stronger, but those without these are in danger of being left behind. In supporting
and championing Forums, we must clearly be careful to recognise some significant financial disparities. In section 1 we report further on the wider contextual factors influencing local support – the presence of participation workers, the levels to which Forums are receiving expenses for representation work and further in-kind support offered by local partners.

THE ENVIRONMENT FOR PARENT PARTICIPATION

Each year we ask Parent Carer Forums to tell us about the quality of their working relationships with local statutory partners in education, health and social care. Their responses are subjective according to their interpretation of the different levels of the ‘ladder of engagement’ – co-production, participation, consultation or information. Nationally, rates of reported co-production peaked across education and social care in 2013-14 – the year the reforms were brought into force. To some extent this is to be expected. Since then, reported co-production has fallen in these areas, whilst growing in health (although admittedly from a lower baseline). Five year trends in reported levels of co-production, participation, consultation and information are included in graphical form in section 3.

THANKS AND RECOGNITION

In 2017-18 Contact is responding to these needs by evolving our support offer to Parent Carer Forums, working closely with the National Network of Parent Carer Forums (NNPCF). We could not achieve this without the strong support of our wider partners in helping to embed cultural change at local, regional and national levels. We are extremely grateful for the continued support of the Department for Education and their contracted partners, including Mott MacDonald, National Development Team for inclusion (NDTi), Preparing for Adulthood (PfA) and the Council for Disabled Children (CDC). We are also delighted to have developed a close partnership with NHS England, the Department of Health and many of the Royal Colleges over last twelve months, and thank them for their ongoing commitment to this agenda.

Our final thanks though must go to the 82,000 parent carers engaged with their Forums across England. Working with the NNPCF, Contact remains extremely proud to have supported and nurtured the development of parent carer participation since 2008. As we approach the 10th anniversary of this programme we have much to celebrate; collectively we have made great strides in embedding participation at the local level, mainstreaming our expectations of co-production with parent carers. There is still of course much to do, but as this report demonstrates we enter the next phase together on firm foundations.
1. AN OVERVIEW OF PARENT CARER FORUMS

GOVERNANCE, REACH, FINANCE AND SUSTAINABILITY: ANALYSIS OF GRANT APPLICATIONS 2016-17

150 (of a possible 152) local areas received the grant funding in 2016-17. Only Tameside and City of London did not apply. Each year a small number of Forums experience significant change or challenge and, for a variety of reasons, find themselves unable to hold the grant. When this happens Contact does so on their behalf, to ensure it can still be used to support participation activity and the re-development of the Forum.

1.1 WHO HOLDS THE GRANT? ABOUT THE HOST ORGANISATIONS

- 58% of grants are held by independent Parent Carer-led organisations, up 10% on the previous year.
- A further 28% of grants are held by Parent Carer-led groups with the support of another organisation.
- Only 5% of grants are not held by a Parent Carer-led voluntary organisation.
- Patterns in grant-holding included a reduction in the number of Forums hosted by local authorities (9 in 2016-17, compared with 15 in 2015-16), and those hosted by Information Advice and Support Service (IASS) – down from 9 to 3.
1.2 Forums’ Governance and Legal Status

In recent years we have seen a clear increasing trend in the numbers of Forums becoming constituted groups. In parallel, we see a decreasing trend for Groups with no specific legal status over the same period. This shows a broadly positive trend in the development of governance structures, whilst noting that around half of Forums are still yet to be constituted.

1.3 Levels of Parent Carer Involvement in Forums

The numbers of Parent Carers connected to a Forum (the blue line) continues to grow, and now stands at 82,000 across England. The numbers engaging in Forum work (using their experiences to affect change – the orange line) shows a flatter trend over the same period (holding steady at around 30,000) though over time this means that the relative proportion of membership engaging in their Forum’s work is declining.
Building on this, if we look at the number of parent carers actively engaged on management or steering groups (the work of running Forums) we see a downward trend: membership may be increasing, and within that engagement numbers are holding steady, but the work of running Forums and fulfilling key positions is falling to fewer individuals. It also means that the scale of their task in representing greater numbers of parent carers in the area is getting harder. We reflect more on these challenges in the diversity and outreach analysis at section 2.2.

### 1.4 Additional Financial Support for Parent Carer Forums

The numbers of Forums generating additional income (on top of the DfE grant) remained static this year at 55%. Since our records began there has been minor fluctuation but no significant change in these proportions – broadly we see a 50/50 split between Forums working from the DfE grant alone and those generating additional funds. This suggests quite a polarised financial operating environment for Forums across the country.

**Further analysis: Forums with additional income**

Though the overall picture remains fairly static we can see the composition of the additional income picture is changing:

- the overall envelope of additional income for the 55% is increasing marginally – £1.385m – a 3% increase on 2015-16.

- Within this there is a tendency towards larger sums – the numbers of Forums receiving additional income less than £10k is decreasing, whilst the numbers of Forums receiving additional income over £25k is increasing.
**OVERVIEW OF ADDITIONAL INCOME AND IN KIND SUPPORT**

**Sources of additional local income**
In 2016-17 we saw a continuation of a recovering trend for additional income coming from Local Authorities – 52% of Forums reported this, up from 47% in 2014-15. Though comparatively the % of Forums receiving additional funding from local health partners continues to be low (8%), we are encouraged that within these figures instances where the local authority and health have combined to provide additional funding has risen in 2015-16 (from 2 to 11 local areas).

**Participation Workers**
Though the % of local areas employing a participation work appears to be declining over time, we do not feel able to draw broad conclusions about what this means in terms of a local area’s commitment to participation (especially when taken alongside the additional income picture above). Anecdotally, we know that it is possible that job titles are simply evolving beyond ‘participation worker’, or that the function is not located within any one role, and/or is being mainstreamed.

**Additional local payments to Parent Carers on strategic bodies**
The number of Parent Carer Forums that said their local authority or health provider made payments to parent carers who sit on strategic decision-making boards or committees, continued its downward trend after peaking in 2013-14.

**Support in kind**
The numbers of Parent Carer Forums that reported receiving support in kind (such as photocopying, or the use of meeting rooms) continued to fall in 2016-17.
2. COMPOSITION OF PARENT CARER FORUMS

2.1 STEERING GROUP, REPRESENTATION AND MEMBERSHIP

Looking at the composition of Forum Steering Groups we can see that:

- 79% of Forums have a steering group comprising of 6 or more individuals;
- The most common size of a steering group remains between 6 and 10 members (50% of Forums); and
- That a noticeable proportion of Forums (21%) rely on five or fewer steering group members.

2.2 DIVERSITY IN PARENT CARER FORUM MEMBERSHIP

The number of Forums using membership or registration forms to collect diversity information about their members continues to increase, and now stands at 57%.

All Parent Carer Forums aspire to reflect the communities they represent, and this year we are undertaking additional research to better-understand this picture. Early findings are revealing that:

- Despite many Forums attempting to collect diversity information on their membership there appear to be significant challenges to doing so, making it difficult for many to have a consistent strategy for their diversity monitoring and outreach practices;
- These challenges typically include a lack of capacity, a lack of information about the communities they are targeting, the difficulties inherent in being ‘outsiders’ to some communities, discomfort in asking for data and a fear of causing accidental offence;
- Where Forums have made progress in engaging seldom heard or harder to reach groups, they have enjoyed most success.
by working in partnership with other organisations. However it can be difficult to evidence the impact of such activity on widening the Forum’s reach.

We will complete the research this financial year and, working with DfE and the NNPCF, use the findings to inform how Forums are supported in their outreach and diversity practice, next year and beyond.

2.3 ANNUAL RECORD OF MEMBERSHIP

In recent years there has been no significant change in the levels of Forums that keep records of demographic details of their membership and steering group. 74% of Forums indicated they did this in 2015-16.

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 very slightly – 74% in 2015-16, up 1% on the previous year. Of those who said that an impairment type predominated, the majority stated that this was Autistic Spectrum Conditions.
3. THE ENVIRONMENT FOR CO-PRODUCTION

ANALYSIS OF 2015-16 MONITORING FORMS

In their grant monitoring, Forums provide their 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, Forums were asked to select the level of participation they feel they have with these partners from the rungs on the ‘ladder of participation’ – information, consultation, participation and co-production.

Readers should therefore acknowledge that the data here reflects a subjective view, based around Forums’ own understanding of these terms at the times of completion. As we are reporting on multiple years, it is also probable that different Forum members, or combinations of members, completed the monitoring in different years. We include these caveats as a warning against drawing too many firm conclusions about what the data tells us, whilst recognising that in many cases the broad national trends do correspond to our qualitative experiences of supporting Forums over a number of years.

3.1 PARENT CARER FORUMS’ ENGAGEMENT WITH LOCAL EDUCATION, HEALTH AND SOCIAL CARE PARTNERS

The graphs below show the combined responses of Parent Carer Forums to the question of which level of engagement they consider they have with local partners in education, health and social care, across a five year period.

EDUCATION

- Rates of co-production are highest during the year the reforms came in (2013-14). At this point nearly 60% of all Forums considered themselves to be co-producing with education partners.
- We see a corresponding dip in participation when co-production peaks, suggesting local areas moved from one to the other at this point. Over time rates of participation have returned to 2011-12 levels.
- Should partners be concerned about the drop in co-production since 2014? Anecdotally we feel Forums’ appreciation of co-production could have improved since 2013-14, meaning they are now holding their relationships to higher standards.
HEALTH

• Though starting from a relatively low baseline compared to education (12% in 2011-12), rates of co-production with health partners do appear to be showing a positive upward trend.

• Like in education, though levels of participation have clearly varied over time, they return to levels similar to those seen at the beginning of the measurement period.

Further health analysis

In addition to the reported levels of engagement above, analysis of the free text monitoring comments indicates that although many Forums report positive working relationships with health partners, this can be limited to a specific service: CAMHS being the most common, a development or redesign of one service (autism pathways, therapies) or with a specific person. As one forum explains:

“*I have chosen co-production but that is specifically in relation to CAMHS. Our working relationship with the wider CCG is best defined as participation*”

Some Forums report better relationships with the health providers, hospitals or community trusts, and others say they have a good relationship with one CCG that covers their area (but rarely all of them). However, a number of Forums are engaging with their local Healthwatch and there also appears to be greater involvement of Forums in re-commissioning activities.

In addition, most Forums tell us they know their DCO/DMO, and that where they do, better engagement follows. Overall, monitoring narrative suggest broad agreement with the data – that there is an improving picture of Forum engagement with health, but still few very few examples of system-wide engagement.
SOCIAL CARE

- The double downward trend in co-production and participation relationships with social care partners would appear to give cause for concern.
- The corresponding increases in reported relationships at consultation and information levels appears to corroborate the drop-off in more meaningful levels of engagement.

3.2 CO-PRODUCTION ACROSS EDUCATION, HEALTH AND SOCIAL CARE

For purposes of comparison, below we reproduce the reported levels of co-production across education, health and social care in one graphic. This allows us to compare peaks and troughs over time, and put the comparatively lower levels of co-production in health and social care in context with those in education.
3.3 ENGAGEMENT WITH SHORT BREAKS SERVICES STATEMENT

Numbers of Forums telling us they co-produced the Statement with their local authority fell to 22 in 2014-15, down from 28 in the previous year. However, reported rates of participation increased during the same period – up to 27 Forums, from 16.

A more significant number of Forums again reported being consulted on the statement (52, up from 34) and the numbers of Forums reporting no involvement fell slightly from 28 to 22. This very mixed picture suggests Forums may need some additional support in managing their relationships with the local authority when it comes to the Short Breaks Statement.

3.4 INVOLVEMENT WITH THE LOCAL OFFER

In 2013-14 126 Forums reported being involved with their area’s Local Offer. We have evolved the question since 2014-15, with an increased emphasis on ‘developing’ the local offer. 57 Forums answered affirmatively.

3.5 REGIONAL ENGAGEMENT

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’s Parent Carer Participation Advisor, and to feed back their views. There has been a slight decrease in the number of Parent Carer Forums able to attend these meetings, down from 86% in 2014-15, to 79% in 2015-16.
4. OUTCOMES OF PARENT CARER FORUMS

ANALYSIS OF 2015-16 MONITORING FORMS

Below we present examples of key outcomes from several forums in each region.

4.1 FROM THE NORTH WEST

Increased knowledge and confidence to participate

‘Over 40 parent carers have had the opportunity to expand their knowledge of SEND reforms and understand their participatory role. We have tailored 3 workshops to reach a wider number of parents at different points of their journey. Understanding the terminology has been an invaluable experience for them, who now feel empowered to join in the discussions.’

Increased outreach and membership

‘We have reached parent carers without digital skills/internet access through hardcopies of newsletters and consultation questionnaires. This has improved their understanding of participation and led to a further increase in forum membership (now 870).’

4.2 FROM THE EAST OF ENGLAND

Increased knowledge and confidence to participate

‘Our parent reps training means they are better-able to work effectively with local authority personnel and more confident and effective in work stream meetings. It also gave our representatives a chance to learn from each other’s experiences and share best practice.’

Enhanced networking and communication between members

‘10 Ambassadors/Reps attended our information day, reporting a better understanding of their roles and what is expected of them. Within a month they had set up their own Facebook page to keep in touch about where they were attending meetings and events, reporting back key bits of information.’

Successful outreach to parent carers of older children

‘We held training on the mental capacity act which increased interest from Parent Carers of those in the teenage age group and opened dialog regarding preparation for adulthood.’

4.3 FROM LONDON

Increase awareness of Forum in local services

‘Our AGM was attended by the Mayor and Director of Children’s Services, 25 parent carers and several professionals. We obtained contact details for all and used them to distribute information about the forum and other voluntary organisations.’

Using events for successful outreach

‘We extend our invitations to other support groups to ensure that we reach as many parent carers as possible, to encourage them to engage and participate. We had 30 attending an event on the legalities of the SEND Reforms. All our events are invaluable to broaden our network and outreach.’
**Parent participation improving services in hospitals**

“We have worked with the local hospital to develop a Learning Disability Flagging system, to ensure staff understand the needs of children, young people and adults with disabilities (as outpatient or inpatient). We are already seeing a huge difference in terms of appointments and admissions, increased awareness of safeguarding issues and in service developments.”

**4.4 FROM THE EAST MIDLANDS**

**Improving perceptions of Forum contributions**

“We have used the SEND transport report to raise personal budget issues. We have presented fact-based parent reports, which has helped balance out the negative experiences we sometimes need to reflect, showing our commitment to coproduction.”

**Governance and Forum development**

“Funding the associate support has allowed us to have an expert’s input into how our forum should be run – it’s also helped us to relaunch the forum.”

**Improved online information and services**

“Having an up-to-date website, has allowed us to reach a wider audience, thereby engaging with more parents and strengthening our Parent Forum.”

**4.5 FROM THE NORTH EAST**

**Parent participation leads to positive service changes in CAHMS**

“We held focus groups with CAHMS and the Family Intervention Team. Parents highlighted a lack of information and gaps in supporting parents whose children have behaviour that challenges. Subsequently we’ve heard a new children’s Crisis Team will be established.”

**Workshops engage high numbers of parent carers**

“We put on a range of workshops to follow up on feedback by parents at our conference. The Sensory Integration Workshop in particular was a massive success, attracting over 50 parents. The new starters day upskilled new starters, ready to take part in the running of the forum.”

**Membership drive leads to increased participation, funding and awareness**

“Through cake and coffee meetings we have attracted 32 guest speakers and increased membership from 115 to 315 and our elected steering group from 9 to 15. New members have also helped source additional funding, enabling us to deliver social, family-based activities.”
4.6 FROM THE SOUTH EAST

Extending influence with the LA and CCG

‘As a result of feedback at our coffee evenings, the LA Commissioning Director met with parent carers and planned cuts to short breaks have been put on hold pending further consultation. The authority have also agreed that changes are needed to social care services, and the new Service Manager for the CYP with Disability Team is coming to our next meeting.’

Outreach to increase diversity and improve representation

‘We have seen a number of new faces over the last year, including from harder to reach groups. This has been helped by our variety of guest speakers. Coffee mornings continue to be an important opportunity for parents to feedback and to share info and concerns.’

4.7 FROM THE SOUTH WEST

Empowering parents

‘Our conference enabled parents to understand the importance of being prepared for transition in education. Our events have increased parents’ awareness and ability to share concerns, and given us opportunity to feedback on the difference their views have made. They also enjoyed working with professionals to improve outcomes for their children. Our evening event reached 48 parents who can’t usually attend daytime activities.’

‘Positive feedback about our parent participation training we put on, included “training was very helpful and made me realise it’s very do-able and not beyond my reach or capabilities. I would definitely be happy to take the next step” and “all information was easy to understand and just the right amount to get you interested and wanting to do more.”’

‘Over 200 attended the Children with Additional Needs Day which included information from 30 providers and consultations on CAMHS, Home School Transport and the Local Offer. 24 new members joined on the day. Members are becoming more confident, asking questions, challenging and seeking clarification.’
4.8 FROM THE WEST MIDLANDS

Using increased membership to extend influence

“We have encouraged new volunteers to take an active role in meetings and consultations, ensuring parent carer voices are heard, acted on and included in as many strategic opportunities as possible.”

4.9 FROM YORKSHIRE AND HUMBER

Facilitating effective participation and co-production locally

“Our family participation days reached those who might not want to come to a conference or information session. They were held at times that allowed dads, working parents and or grandparents & siblings to attend, providing a stepping stone to greater participation and to meet other parents. This also improves our ability to represent on more work streams.”

‘Holding open forum events helps to continue building relationships between local services and parent/carers and networking with local voluntary organisations. This provides continual feedback to parent/carers and shows examples of partnership working and opportunities for co-production. Bigger events also provide support groups with an opportunity to work together by identifying important issues that relate to all families across many different disabilities. In addition positive links were made with local MPs. Parent carers have met each, built confidence, participated in giving their views on important changes to services and offered different ways to become involved in forum activities in future.’
5. ACHIEVEMENTS OF PARENT CARER FORUMS

5.1 FROM THE EAST OF ENGLAND

Co-production in CAMHS – we have moved from raising concerns to being an active partner in discussions over the new system and funding. We are also working closely with another voluntary organisation to deliver training/support to families waiting for/accessing CAMHS.

Breakthroughs in local health relationships
‘Our achievements include joint work with the CCG and a bordering forum to gather parents’ views on mental health services and provide the services requested. We were involved in the development of an Activities Passport with a voluntary organisation and the local authority.’

5.2 FROM THE NORTH WEST

Local review recognised as national good practice
‘The Disabled Children Service Review has involved a work stream with parents and professionals working together as equal partner and has been recognised by CDC as a model of good practice.’

Significant positive engagement with schools and education partners
‘Parents spent 3 months planning/delivering a Schools Training aimed at School Leads, SENCO’s and Pastoral staff. We informed schools about good and bad experiences and how schools and families can work together. The event also included a number of other presentations for parents and external groups. Reps from 30+ schools also attended workshops to help them engage more with families, provide info and share best practice.’

5.3 FROM THE NORTH EAST

Increased membership
‘We have increased membership over the last 12 months to 260+. We have recruited a very active group of parents, including reps on a number of LA work streams and steering groups. We have also influenced the development of a Children’s Crisis Team through with CAMHS.’

Successful Short Breaks review
‘We have worked with the local authority to carry out a successful short breaks review and ensuring that this coming year will be even better for families accessing short breaks.’
5.4 FROM LONDON

Engaging hard to reach communities

‘We have reached many more parents, including younger parents and those in the Turkish-Kurdish communities, through use of interpreters and consistent use of texting in different languages.’

Working in partnership across the Local Authority to achieve positive outcomes for parents

‘We worked with the LA on induction training for new employees, identified parents to be part of interviews, recruiting staff/keyworkers and even the ED of Children Services. We also successfully worked with parks to install a wheelchair swing – an exemplar in accessibility.’

Using events to boost membership and feedback

‘Our Parent Conference had 140 parents, added 79 to our wider membership and recruiting a new Steering group member. Feedback from 70 parents will also help us plan future events/meetings.’

Co-production leading to cost efficiencies

‘We published a Guide to Reasonable Adjustments, co-produced with the local authority, and celebrated by national figures and all local schools! We carried out an SEN Transport consultation resulting in a revised, co-produced joint policy and leading to cost efficiencies.’

5.5 FROM YORKSHIRE AND HUMBER

Refreshing the relationship with the Local Authority

‘At the start of the year it felt as if our LA was moving away from true partnership working. We have been able to partially reverse this trend and now meet with the Director of Children’s Services, making progress on stuck issues such as the further development of the local offer.’

Building up our Forums

‘Increasing membership, having a paid participation worker, getting a co-production charter.’

‘Holding our 1st Annual Conference and successfully rebranding the Forum’
5.6 FROM THE EAST MIDLANDS

Social media buzz
‘Increasing in our social media platforms as a means of communicating with parents and carers, allowing them to pass on information, share posts, comment and create a ‘buzz’.’

Maintaining a close partnership with our host organisation
‘Sustaining financial support from the LA allowing our host to continue supporting us for another 12 months. This maintains our ability to strategically position ourselves as the legitimate voice of parent carers.’

Fundraising success
‘Securing Big Lottery Funding for 5 years. Being recognised as the forum to deliver P&E by the LA – taken seriously!’

5.7 FROM THE SOUTH WEST

Governance and outreach
‘Becoming a constituted group and fund-holder, developing a parent carer guide and running two events in one day to reach working parents.’

Supporting independence
‘We have been involved in the design/build of 4 self-contained flats for vulnerable young people with challenging behaviour, to develop independence and have a short break. We have also been involved in developing support for parents of children with mental health issues.’

Working in teams
‘Developing teams of parent representatives for different areas such as a Post 16. Working as a team of representatives rather than as an individual has been really successful for our forum.’

5.8 FROM THE SOUTH EAST

Community and school outreach
‘Engaging with some parents from identified hard to reach areas and also making contact with a couple of mainstream schools and being invited in.’

Governance and strategic footprint
‘We presented our first Annual Report as a Charitable Incorporated Organisation. We established a regular parent meeting in a new area of the County. We have developed our strategic role at County level, especially with the SEND team and in Commissioning.’

Building momentum
‘Members have had training in emotional resilience, impacting on collaboration within the group and developing empathy and support for others. Some are now looking into befriender training. We have done a significant amount of work with Education and Social care and are looking to be part of the strategic groups. Parents are now much more pro-active. We have good links with the school and SENCO. Building all of this momentum is a major achievement.’
5.9 FROM THE WEST MIDLANDS

Strategic relationships with the LA and professionals

‘Having a much-improved relationship with the Local Authority, being named as the “go to” organisation for Parental representation on stakeholder groups and other meetings related to SEND reforms. Participating in 2 successful Family Conferences, exhibiting as equal partners.’

‘Parents championed by the Director of People and involved right at the beginning of the design of the whole life disability service. Parent involvement on the SEN Strategic Group.’

‘Having a separate parent-only group (for the first time) is working better than a steering group that also previously included professionals (although they remain keen to work with parents.’
6. CHALLENGES FOR PARENT CARER FORUMS

ANALYSIS OF 2015-16 MONITORING FORMS

Finally, we asked Forums to tell us about some of the key challenges they experienced last year.

6.1 FROM THE EAST OF ENGLAND

Engaging with social care
‘Despite being a previous focus of ours, and the continued difficulties for parent carers in accessing appropriate social care support, we have been unable to develop an effective working relationship.’

Moving to a new grant holder
‘The move to a new grant holder has been challenging, but the Forum are very pleased with their new relationship. Information and financial matters are dealt with competently/quickly so the Forum feels more in control of the budget and can make informed decisions.’

6.2 FROM THE NORTH WEST

Starting up
‘As a new forum, getting parents interested, professionals to take us seriously, invited to meetings.’

No opportunities for co-production
‘The LA decided to stop all of the SEND reform work streams, leaving little opportunity for coproduction. We have struggled to attract parent volunteers who are able to engage outside of steering group meetings, and the lack of involvement opportunities has exacerbated that.’

Forum capacity
‘Capacity continues to be a constant challenge, with active members moving away (for various reasons) and new members needing intensive support to feel confident in active participation.’

6.3 FROM THE NORTH EAST

Forum capacity
‘We had two office moves in a year which has been really challenging – especially keeping everyone informed and the extra administrative work created.’

‘Re-structuring of the local authority has created challenges for our forum.’

Ensuring the forum is still involved in co-production post SEND reforms agenda
‘Senior officers have been so busy actually implementing the reforms that some of the meetings have had to slide. They are now starting to be reinstated with new targets and reviews taking place.’
6.4 FROM LONDON

Volunteer capacity
‘It has been challenging to retain the volunteers we have invested considerable time in training, with not enough people able/willing to attend strategic meetings.’

Engaging health
‘We have struggled yet again to engage with some health officers, but we do now have a CCG link and are hoping to forge greater links. We intend to work with Healthwatch to help us develop further links and ensure health professionals attend meetings regularly.’

Losing LA resources
‘Losing an administrative worker from the local authority, including all office equipment, has been a real challenge. We have had to re-organise the forum’s work in different ways.’

6.5 FROM YORKSHIRE AND HUMBER

Recognising the contribution and expertise of parent carers
‘Forums having more knowledge and expertise than many professionals working in the field, fortunately this well recognised, accepted and utilised here. Parents need to be given credit for their abilities and recognised as such.’

Engaging health
‘Relationships with Health (DMO) are strong but capacity means they don’t attend reviews and have minimal input into plans. Engagement with the CCG is friendly but not at co-production yet – the Forum’s value, support and knowledge not fully recognised/acknowledged.’

6.6 FROM THE EAST MIDLANDS

Capacity and fulfilling strategic opportunities
‘Accommodating all the new work streams and strategic meetings we have been invited to attend. Share of work within the Steering Group is too much sometimes as too few people doing the majority of the work. Need to increase Steering group and train them up to take on more responsibilities.’

‘Sustaining and maintaining the roles of Sub Hub Co-ordinator. 3 of the 4 parent carers have had to step down or reduce the amount of time they can commit due to personal or work issues. Recruiting new members and getting new members to attend Sub Hub Meetings.’

Engaging health
‘Getting Health and social care to engage effectively and with some urgency.’
6.7 FROM THE SOUTH WEST

Fostering participation in a challenging financial climate

‘Being the bearer of bad news – consultations are often driven by the next round of financial cuts and the need to work with parents to explore how to implement savings and reduce the negative impact.’

Forum capacity

‘A lack of members and therefore recruitment. It’s difficult to recruit parent carers with the time to contribute. Members have many ideas but often the capacity to achieve them is not available.’

Continuity with local partners

‘Reorganisation at the LA and health – key staff leaving and pieces of work not being moved on.’

6.8 FROM THE SOUTH EAST

Engaging with Social Care

‘Getting social care to open the door to co-production and making sure that we were still at the forefront of service development now the SEND reforms were down to “business as usual”.’

Forum Capacity

‘Maintaining the steering group – personal pressures, health issues and not enough parents. We have used our wider forum but it is difficult to receive the feedback we need. We are working on increasing our steering group, with each member responsible for supporting others and sustaining the group.’

Members’ caseload

‘Dealing with persistent parents’ cases – some EHCP’s don’t meet expectations or aren’t finished on time. Some services are removed or there’s a lack of provision (budget cuts) or changes in the structure of one of our special schools has a negative impact.’

6.9 FROM THE WEST MIDLANDS

Forum Capacity

‘We have a really good understanding of our role but there is too much work for too few people. Recruitment is a problem, as is the fact that we have stressful and busy lives already. When most people volunteer for anything it is usually because it is rewarding, we sometimes feel that we have acquired a frustrating unpaid job complete with reams of paperwork, emails to be checked daily, meetings to attend, and deadlines to be kept.’

‘It has proved particularly challenging to maintain families’ engagement in the development if the new system when they are not on the whole experiencing the benefits. Those supporting young people in Post-16 are becoming very disillusioned and feel the new system is as promised.’
7. CONTACT SUPPORT TO PARENT CARER FORUMS

7.1 OUR CORE OFFER

All Forums continue to be able to access a core offer of support, which includes access to a named Parent Participation Advisor (PPA) and additional support through our pool of Associates where necessary. Our PPAs are the first point of contact for Forums, offering advice and support via telephone, email and in person. We provided over 4,000 hours of 1-2-1 support for Forums in 2016-17.

PPAs work in close partnership with their regional NNPCF Steering Group members, attend regional network or cluster meetings and support Forums with their grant applications and monitoring submissions. PPAs also offer support to Forum’s strategic partners, and in doing so raise the profile of participation and the importance of co-production. Feedback on monitoring forms shows how much this direct support is valued.

‘We have been well supported, especially with the challenges we have had to face this year, always helpful, quick communication through e-mail or left messages by phone. We feel without this support we would not have overcome some of our challenges.’

• ‘Having the Advisor is key in providing Forums with support, advice and guidance.’

• ‘Contact (a Family) are very supportive to our forum. They are always actively involved within events and provide sound information when we have queries.’

• ‘Fantastic – our regional advisor is so approachable and knowledgeable.’

We recognise we can’t always meet the needs of every Forum and that sometimes the governance and accountability requirements of the grants process can seem to be at odds with those of the Parent Carers applying, whom we recognise as volunteers with busy and often challenging lives. We welcome their feedback and use this to inform the services changes we make year on year. Examples this year include:

• ‘More time is needed to complete the Monitoring & Reporting Forms.’

• ‘Maybe a monthly call or email to the forum to see how they are coping or if they have any issues.’

• ‘We have been well supported, especially with the challenges we have had to face this year, always helpful, quick communication through e-mail or left messages by phone. We feel without this support we would not have overcome some of our challenges.’
• ‘Forums should be given the opportunity to meet all other forums in a regional annual event (Marketplace style) to foster good relations, promote cross area working and to peer support the localities.’

• ‘To increase more face to face training for forums.’

• ‘If possible – to make the forms shorter.’

### 7.2 Intensive Support for Parent Carer Forums

Sustaining and developing parent carer participation can be extremely demanding for Forums, as they are on the capacity of parent carer volunteers. Expectations from local and national partners (as well as the additional parent carers in their area that they represent) puts a lot of additional demands on these very dedicated people, which can inevitably lead to stressful situations. For these reasons, we retain a pool of skilled associates who can provide additional, targeted support to Forums, local authorities, health partners and other stakeholders with specific issues or challenges.

In 2016-17, 32 Forums took up this offer to help them strengthen their steering group, their relationships, their membership or their governance.

‘Contact a Family went above and beyond this year to help us resolve the issues the forum had. We had an associate who came to help us; her advice and support was invaluable, along with our regional advisor. We are very grateful to the whole team this year they have been amazingly supportive and have helped us through this year to become a much stronger forum.’

• ‘We have had help from an excellent Associate this year and wouldn’t be where we are now without her input and support.’

‘Been very happy with the support provide by the associate – it has meant queries and issues have been dealt with promptly-and has helped with our capacity.’
7.3 Learning, Development and Networking for Parent Carer Forums

Annual National Parent Carer Forum Conference

On 1 November 2016, 211 attendees from 88 parent carer forums from across England met to discuss ‘What’s next for participation?’ at our annual joint conference with the NNPCF. The event celebrated the progress made in putting parent carers at the heart of the decision-making process. A speech delivered on behalf of the Minister of State for Vulnerable Children and Families, Edward Timpson MP, thanked Parent Carer Forums for their hard work, and for the commitment of the NNPCF and Contact a Family in leading the way in embedding co-production. Feedback was very positive, demonstrating how delegates valued the opportunity to network with other Forums.

Webinar learning series

Throughout 2016-17 we delivered a series of 10 webinars helping us reach Forums across all regions. Forums view webinars as valuable learning sessions, accessing them live and post-broadcast via YouTube. Subject matter varies across capacity-building activities and thematic topics, chosen by Forums and delivered by in-house experts, Forum representatives and external partners. Collectively these reached over 1200 individuals. Comments about this year’s series included:

• ‘A good way to get information and a level of interaction with asking questions and getting answers.’

‘Brilliant and made relevant to forums rather than generic.’
We work closely and collaboratively to strengthen the message about the importance and value of co-production with a wide range of national stakeholders, and share the common aim of empowering parent carers to be at the heart of all decision-making that affects them and their families.

7.5 SEND SURVEYS

In 2016-17 we ran two SEND reforms surveys for Parent Carer Forums mirroring those that the DfE sent to local authorities to review progress in the implementation of the reforms. The information provided by local authorities and Forums is triangulated and helps to inform the support offer to each area. Full reports are provided separately to the DfE, with an anonymised summary report made available publicly.

7.6 WIDER STRATEGIC PARTNERSHIPS

Contact 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.

In 2016-17 we engaged fully in the SEND Regional leads programme and the SEND Leadership programme, ensuring the importance of co-production is a key message in local areas. We have worked in partnership with our colleagues in the DfE Advisory Team to ensure a collaborative approach is taken to implement the cultural change required to embed the reforms. We have strengthened our work with colleagues from NHSE and have started to see real progress in the health colleagues engage with us, Forums and the NNPCF.
This year we have also initiated Voices – the National Alliance for Local Area Partnership Working. The purpose of the Alliance is:

To ensure that we have a nationally agreed framework, process and principles for whole area co-production and participation that can be used in partnership by all stakeholders in each local area (Social Care, Education, Families and Health) in England.

These should capture the shared values that all Alliance members have in relation to participation and co-production and reflect the intent of the Children and Families Act 2014 in ensuring Families, Parent Carers and Children and Young People are fully involved in individual and strategic decisions that affect them. They should also support The Health and Social Care Act (2012) and the NHS Constitution (2015) in which co-production at an individual and collective level is a core theme.

We look forward to developing this Alliance further and to welcoming new members in the future.
HOW WE WORK TOGETHER

The NNPCF is the national representative voice of local Parent Carer Forums. Contact fulfils an enabling and capacity-building role for the NNPCF and Forums.

Contact
We are Contact, the charity for families with disabled children. We support families, bring families together and help families take action for others.

NNPCF
The National Network of Parent Carer Forums is a membership organisation and national voice of Parent Carer Forums in England.

Parent Carer Forums
Parent Carer Forums are volunteer-led groups of parent carers of children with SEND, working strategically with local partners to ensure the local voice of parent carers is at the heart of decision-making.

Contact administers local grants and provides capacity-building support for Forums.

All parties share a strong commitment to embedding co-production at local, regional and national levels.

Local Forums come together in regional networks, through which a recruitment process selects NNPCF Steering Group members, who collectively represent the national voice of all Forums.

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

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

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**CONTACT THE NNPCF**

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GET IN CONTACT

FREEPHONE HELPLINE

0808 808 3555
Access to interpreters
helpline@contact.org.uk
www.contact.org.uk
Open 9.30am–5pm Monday to Friday

Our freephone helpline can give advice about any aspect of raising a disabled child, including help with finances, education, emotional and practical support.

Contact Head Office
209-211 City Road
London EC1V 1JN

020 7608 8700
info@contact.org.uk
www.contact.org.uk

GUIDES FOR PARENTS

We have a range of free guides for parents, including:

• Helping your child’s sleep
• Claiming Disability Living Allowance
• Siblings
• Fathers

All our guides are free to parents who call our helpline, and are free to download.

www.cafamily.org.uk/publicationslist