



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

# Engage Enable Empower!



## Annual Report

April 2017 - March 2018

National Network of Parent Carer Forums

October 2018

#LetsParticipate18

# NNPCF Annual Report 2017-2018

Our Annual Report provides information about the National Network of Parent Carer Forums (NNPCF) and shares the work we have done during 2017-18.



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Report compiled by Sharon Smith

# Introduction and Welcome

## Welcome from the Co-Chairs of the NNPCF Steering Group

Welcome to the 2017-18 Annual Report from the National Network of Parent Carer Forums (NNPCF.)

The 31st March 2018 was a date etched on our minds, as it marked the end of the implementation period for the Children and Families Act. As a result, this was a focus of much of the work our member forums, as well as the NNPCF Steering Group. For some Local Authorities the transition was a smooth ride, but for many it was a messy scramble. Parent Carer Forums and the Steering Group worked hard to give voice to parents and carers across the country during this time and we represented your concerns about the quality of Education Health and Care Plans, the experiences of children with SEND in mainstream schools and the difficulties we face when our children leave education. Although the implementation period for the SEND reforms is over, we cannot say that the aspirations of the reforms, or of families, have yet been met.

However, within this difficult context, we also know that parent carer forums are making a real difference to the lives of children and young people with SEND. Whether it be re-shaping services, training practitioners or bring families together, we are delighted to be able to share some of your successes in this report.

This year also marked ten years of funded parent participation and co-production. As Co-Chairs of the NNPCF, we are privileged to be part of the journey that Parent Carer Forums and the NNPCF have taken. The early days of parent participation saw pioneering forums scattered around the country taking on the

idea of working in partnership with professionals to improve outcomes. They developed this idea further and shared their successes, following which, the number of forums increased substantially and at a great pace.

These visionaries recognised the need to bring together the voices of parent carers, so that they could be heard locally, regionally and finally nationally, to improve outcomes for families. Did they know what they were starting and how it would look today? Probably not, but we hope they feel that we have kept to the ideals that they imagined.

As ever, we would like to take this time to thank all our member Parent Carer Forums for their drive, commitment and dedication. We cannot thank all the individual parent carers involved with their local forums enough, for all their hard work and valuable contributions. Without the key input from our Parent Carer Forums we would not be able to make a difference at strategic levels and to outcomes for families of children with Special Educational Needs and/or Disabilities (SEND).

Whether your forum has been around for a long time or was formed recently, we are pleased that you stand with us to form the National Network of Parent Carer Forums, so that we can honestly and proudly say:

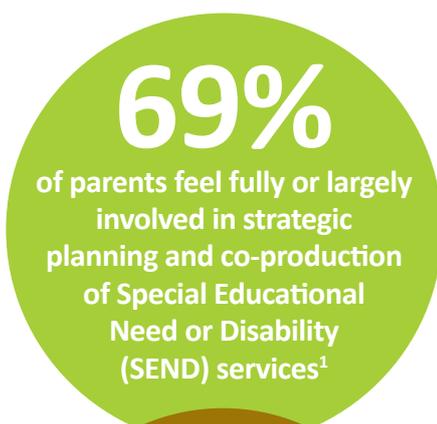
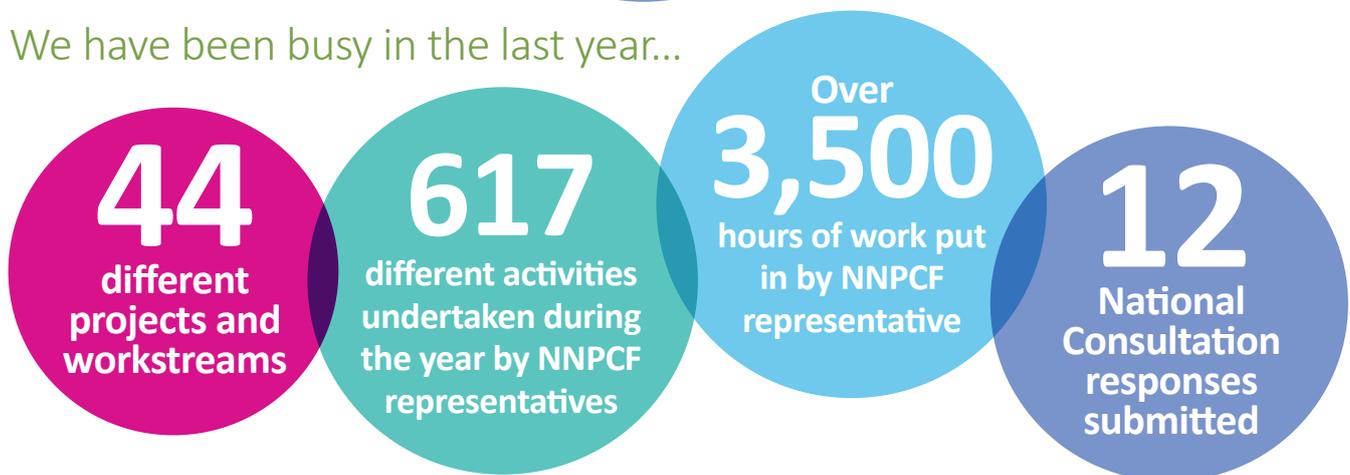
**“Our Strength is our Shared Experience”**

**Maureen Morris** and **Mrunal Sisodia**  
Co-Chairs, NNPCF 2017-2018

# A snapshot of the year



We have been busy in the last year...



How do forums and families feel about co-production?

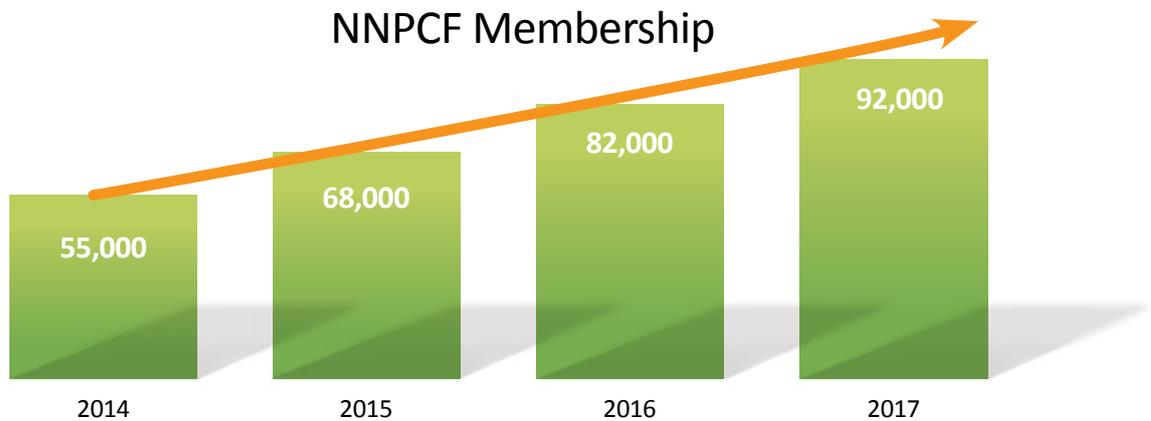
“Very informative meetings. Interesting to meet other parent carers, share views and experiences. A great opportunity to get involved and shape services with the local authority, for all parent carers with children with SEND”  
– Poole

“The situation parents of children with SEND find themselves in gets harder every year, it seems, due to cuts to almost all supporting services and we think our collective voices are more important than ever.”  
– Ealing

<sup>1</sup>Source November 2017 SEND implementation survey

<sup>2</sup>Source November 2017 SEND implementation survey

## NNPCF Membership continues to grow...



## We've made a big difference:

- The Department for Education (DfE) have recognised our concerns about the quality of Education Health and Care Plans
- Improving the experiences of children and young people with Special Educational Need or Disability (SEND) in mainstream schools has been prioritised by the Secretary of State for Education following feedback from our members.
- Ministers across the Department for Education (DfE) and the Department of Health (DoH) and Social Care have committed to lead, model and drive joint working across departments
- The programme of local area inspections has been extended beyond 2021. Areas with a written statement of action are to be re-inspected.

But there remains a lot for us to do:

- We continue to raise concerns that local areas are struggling to meet their obligations to children with SEND against the backdrop of constrained resources.
- The disability employment gap remains high at 31% with too many young adults with SEND ending up as NEET (Not in Education, Employment or Training)
- No-one would say that we have yet delivered on the aspirations of families and the requirements of the Children and Families Act 2014.

# About the National Network of Parent Carer Forums (NNPCF)

## Our mission and vision

The National Network of Parent Carer Forums (NNPCF) is the independent national voice of Parent Carer Forums.

**Our mission** is to deliver better outcomes for families living with special educational needs and disabilities (SEND). We aim to:

- create a culture of participation and co-production across the education, health, social care and the voluntary sectors. This means that we are involved in all aspects of designing, commissioning, delivering and reviewing services as an equal partner.
- empower our members to ensure that their voices are heard at a local, regional and national level
- inspire our partners by sharing good practice and knowledge.

**Our vision** is for the best possible opportunities and futures for all children and young people with SEND and their families.

## Who are we?

The National Network of Parent Carer Forums (NNPCF) is a parent carer led organisation, which has a network of 151 local Parent Carer Forums (PCFs) nationwide. Our role is to champion strategic parent participation at a local, regional and national level.

Each of the local Parent Carer Forums work within their region, and each region is represented by their National Steering Group member(s). The Steering Group is made up of ten members who are recruited with the support of their region; they represent the nine regional areas in England (with two based in London) to ensure that the collective voices of members of local Parent Carer Forums are heard at a national level by working together.

“Parent Carer Forums are representative local groups of parents and carers of children and young people with disabilities who work alongside local authorities, education, health and other service providers to ensure the services they plan, commission, deliver and monitor meet the needs of children and families”

**Para 1.13 SEND Code of Practice 2015**

## Who are the Steering Group members?



**1** **Maureen Morris**  
North East  
& Cumbria



**2** **Julie Bruce**  
Yorkshire  
& Humber



**3** **Kath Bromfield**  
North West



**4** **Dave Nutting**  
East Midlands



**5** **Zara Bowden**  
West Midlands



**6** **Mrunal Sisodia**  
Eastern England



**7** **Fazilla Amide**  
London



**7** **Kay Moore**  
London



**8** **Lara Roberts**  
South East



**9** **Tina Emery**  
South West

## What is Parent Carer Participation?

Parent carers have parental responsibility of, or care for, children and young people who have a Special Educational Need or Disability (SEND).

Parent carer participation is when parents and professionals, commissioners and policy makers work together, recognising each other's expert knowledge, to design, commission and deliver better services for children with SEND.

We use the Ladder of Participation approach, which supports the membership and the Steering Group to become involved at a local, regional, and national level as well as to develop and influence strategic policy making and commissioning processes.



An equal and reciprocal partnership where everyone's experience, knowledge and skills are used to create better outcomes

**3**

'A way of working where children and young people, families and those that provide the services work together to create a decision or a service which works for them all.'

**Definition of Co-production,  
Local Area SEND Inspection letters**

<sup>3</sup> <http://www.participatorymethods.org/sites/participatorymethods.org/files/Arnstein%20ladder%201969.pdf>

## Our work



## Listening to our membership

The lived experiences of our members form the basis of everything we do. We use a variety of means to listen to our membership.



Over the course of the year we:

- attended nearly 100 regional meetings and events
- conducted three member surveys
- sought feedback on 12 consultations and calls for evidence
- learnt from 900 discussions on our closed Facebook pages and over 10,000 comments and reactions
- held a two day national conference attended by over 200 representative delegates.

## What do parents think?

“This group has helped me loads as a parent they have made me see there is a light at the end of the tunnel for my son, they always give me advice when I am feeling down and makes me feel on top again with their support, just a massive thank you to you for all the help you have given me so far.”

**Somerset**

“Having attended this morning’s meeting, I have more mental energy than I have in a long time. It was really cathartic to be able to speak openly, to rant even. I learnt so much from you and the other parents, I learnt more over that my children and us as parents matter. My husband and I have kind of slipped into a slump of daily grind and worrying constantly, never believing that we could at least help change. In fact, I feel normal for once.”

**Bedford Borough**

“Learning to live again after diagnosis is a bit like learning to swim: yes, you can get pushed into the deep end and as you desperately flail around you end up learning to swim, although most probably it’s a case of learning to just tread water. If on the other hand you are taken gradually from the shallow to the deep end by a more experienced swimmer then you are most certainly going to be a strong swimmer. So when a parent of a newly diagnosed child says, after attending the first co-hosted Parents’ meeting between the City Parent Carer Forum (CPCF) and the City of London Local Authority “we thought we would be alone through this but now realise we won’t be”, you know that once they have regained their orientation, once they have formed new, healthy relationships, their capacity for Parent Participation is going to be phenomenal and a potentially isolating situation can turn into something that bears a lot of fruit.”

**City Parent Carer Forum**

# Shaping our priorities

Having heard and understood what our members are telling us we work with our local forums and regional networks to create a national picture of the issues, themes and priorities of children and young people with SEND and their families.

For 2017-18 we identified the following priorities for the NNPCF. We review these priorities on an ongoing basis and change them depending on what we hear from our membership.

## 1. Co-production

- Work to embed the culture and practice of co-production with our partners and champion coproduciton at a local, regional and national level. Develop all of our key strategies and policies in co-production with our member forums

## 2. Effective services for children and families

- Education Health and Care Plans
- SEN Support
- Preparing for Adulthood
- Joint commissioning
- Transport
- Local Area Inspections
- Engagement with Health
- Short breaks
- CAMHS

## 3. Build the capability, capacity and sustainability of forums

- Continue to grow our membership
- Ensure strong regional networks
- Manage the NNPCF effectively

**We are in the process of writing talking points for our key priorities that detail**

- The lived experience of our members about each topic,
- What is working and what is not working, and
- What we would like to see changed

You can find a list of our current talking points at

<http://www.nnpf.org.uk/about-the-nnpf/talking-points/>

# Working with our partners

Our team of National Representatives works with our partners, to ensure that they understand the lived experience of families of children and young people with Special Educational Needs or Disabilities (SEND). Our national representatives are all parents and carers of children and young people with SEND and are able to put forward what we hear from forums in a direct, honest and authentic way.

To learn more about our team of National Representatives, please take a look at our website <http://www.nnpf.org.uk/about-the-nnpf/nnpf-national-reps/>

## **The National Representatives work with our partners in a range of ways that includes:**

- Raising specific issues with them as they arise
- Having places on boards and governance bodies of relevant groups, organisations and projects
- Responding to formal consultations on behalf of our members
- Participating in specific projects, investigations and reports
- Meeting face to face and corresponding with our partners.



*As new ministers arrived in the year, national representation of NNPCF, led by the Co-Chairs has been incredibly useful at getting parents' wishes on a ministerial agenda.*

**Dame Christine Lenehan**  
Director, Council for Disabled Children

## Here are the partners we have worked with over the course of the year and some of the projects and activities we have engaged in.

**Organisations the Steering Group and National Representatives have worked with in 2017-18:**

Contact (previously known as Contact a Family)

Care Quality Commission

Council for Disabled Children

Delivering Better Outcomes Together

Department for Education

Department for Work and Pensions

Department of Health

Independent Supporters

Mott McDonald

National Development Team for Inclusion

North East 12+ Network

NHS England

Ofsted

Regional Lead Programme

Preparing for Adulthood

Regional Directors of Childrens Services

Regional SEND Network

Special Education Consortium

NHS England Regional Teams

London Strategic Managers Network

London Councils

British Association for Supported Employment

NASEN

IPSEA

The National SEND Forum (Federation of Leaders in Special Education)



*The DfE SEND Adviser team has valued the strong links it has with NNPCF, which has enabled fruitful discussions with LA PCF representatives in every region about what has been going well, and where there are specific issues for support and challenge. It was particularly helpful in sharing information about progress with transfers of statements ahead of the completion date of 31 March 2018. Training and development is also an area where there have been strong links, and the active contribution from PCF representatives at the SEN decision-making and redress workshops, for example, has been valued.*

**André Imich**

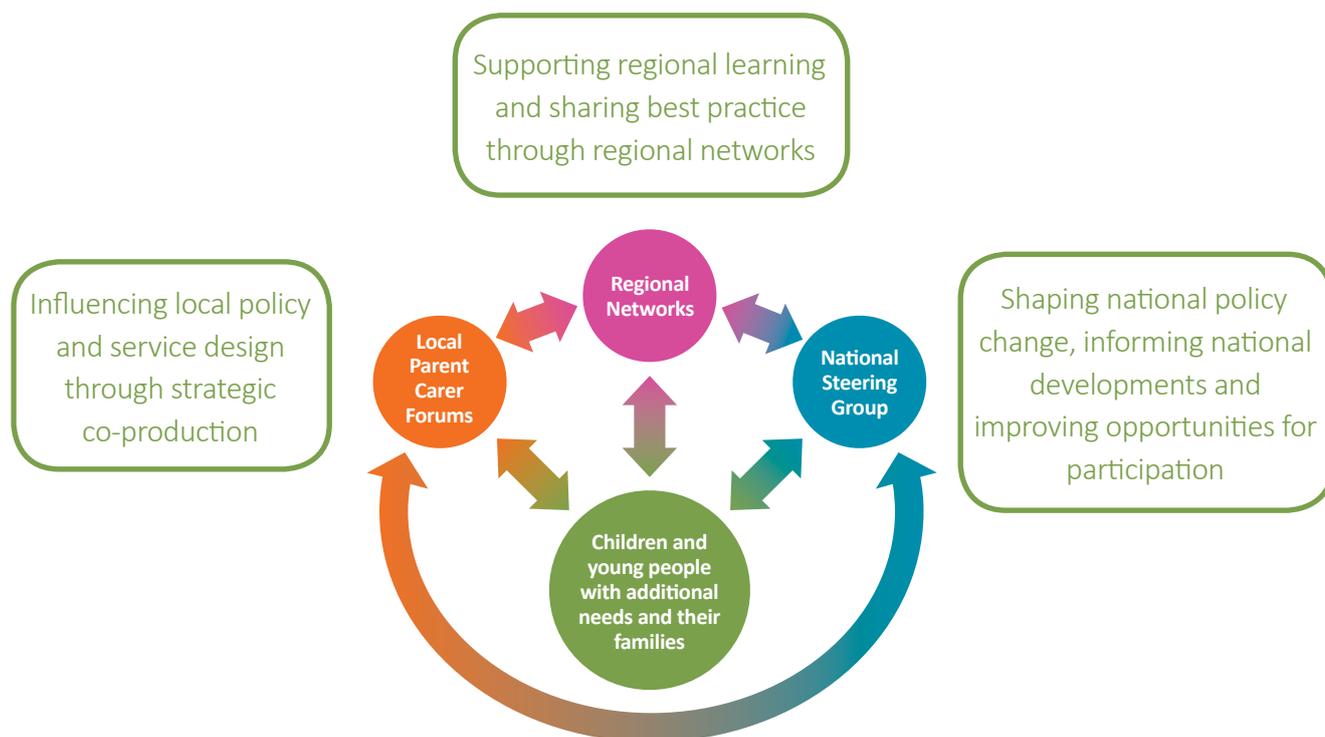
SEN and Disability Professional Adviser, Department for Education (DfE)

**Some of the projects, boards and reviews the National Representatives have contributed to:**

- SEND Single Route of Redress National Trial
- Early Years Send Project Advisory Group
- Workshop on Improving Social Care Outcomes
- Social Care Regional Training
- SEND mediation working group
- WAG Personalisation Budgets
- Children with Complex Needs SEND Board
- SEND advisory board
- Childcare Works 30 hours
- Whole School SEND
- NHSE Parent Participation Events
- British Association of Supported Employment Conference
- Ofsted / CQC training
- Lenahan review
- Bercow – 10 years on
- Rochford review
- The National Alliance for Partnership Working

# Our activities and achievements

We work at a local, regional and national level to improve the lives of children and young people with SEND and their families.



“Our strength is our shared experience”

2017-18 saw the end of the implementation period for the Children and Families Act and has been one of the most interesting years yet for the parent carer forum movement.

Against a backdrop of tightening resources, improving the outcomes for children and young people with SEND has been harder than ever, despite the aspirations of the legislation. However, Parent Carer Forums have continued to work tirelessly in their local communities, across their regions and nationally to make a difference.



*Myself and the team at Mott MacDonald have continued to work closely with the NNPCF over the past year. They are passionate about what they do and fully committed to ensuring the collective views of parent carers, children, and young people are listened to and considered at all times. The NNPCF have been particularly active in attending and supporting our work through events and workshops both nationally and regionally as well as providing challenge when it is needed. I would personally like to thank all those we have worked with over the past year for their support and challenge and look forward to continuing this relationship into the future.*

**Scott Boyd**

Programme Manager DBOT, Mott MacDonald

## Local Parent Carer Forums



Parent Carer Forums across the country have played an instrumental role in stopping changes that might otherwise have had a terrible impact on families. Across the country, there have been numerous examples where local areas have made proposals that have been withdrawn or changed following interventions by Parent Carer Forums.

In **Cornwall**, **Central Bedfordshire** and **Knowsley** proposed changes to Transport policies were halted; the forum in **Merton** successfully challenged changes to ASD pathways and in **Bedford Borough**, the forum stopped changes in short breaks services.

Forums have been involved in training and upskilling the workforce. **Luton** forum held an inspirational event, that tracked the life journeys of two families with SEND using amateur actors; the two **Bedfordshire forums** have running training on outcomes focus and person-centred planning for practitioners.

Forums have also had a key role in developing joint working relationships, an area that is a weakness across the whole country. **Wiltshire** forum was involved in the development of a combined 0-25 SEND team and social care service, **Hertfordshire**

forum helped to co-produce a 0-25 social care service and Portsmouth had a hand in placing the identification of short breaks needs as a part of the annual review process. Co-production with Health has been a key factor wherever joint working has been progressing. **Lincolnshire**, for example, have been involved at every strategic group and workstream and every consultation and reflection meeting.

More and more forums like in **Liverpool** and **Poole** are co-producing their local offer and producing information that is sent not to just parent carers but practitioners within the local authorities and health. They are also improving strategies and policies, making them accessible to the wider audience.

Forums play an active role in organising events that bring the SEND community together and share information. Some highlights included **Milton Keynes'** information day at which they recruited

13 new members and 2 new parent representatives, **Bromley'**s open day for families of children with SEND in mainstream schools that included everyone singing together, and finally Bolton's event which ended up in a young person with SEND getting a job with one of the independent stall holders that attended!

We know that there is some outstanding work being done in other parts of the country, but we are also keenly aware of the challenges some forums face day in and day out. The goal of the NNPCF is to have every parent carer forum in a position to share the good practice of participation. We will achieve this by continuing to work nationally with our strategic partners to raise the concerns of those forums, along with Contact as the DfE contract holder whenever forums report difficulties, and additionally by providing opportunities for forum to forum support, which time and time again has proved to be so valuable.



*“Parent Carer Forums have become an embedded way of working within local areas and act as a key point of reference for CDC. This year they have been particularly helpful in supporting the work of Independent Support – both promoting it and challenging it when needed. They have also been really helpful when areas have got stuck and in promoting really good co-production.”*

**Dame Christine Lenehan**

Director, Council for Disabled Children (CDC)

“Our parent carer forum are simply fantastic, they are some of the best people I have had the good fortune to work with. I cannot pretend to have the same experiences, but I can commit to respecting the experiences of parent carer forum colleagues, listening to them and learning from them. In my view it is quite simple – a failure to co-produce with the parent carer forum equals a failure in the commitment of partners to improve outcomes for children and young people with special education needs and disabilities.

“ There have been many successes over the past few years, here are three examples;

1. The excellent needs analysis work undertaken by the parent carer forum and their leadership of the joint strategic needs analysis created a robust evidence base to secure capital funding for a brand new 200 place special school.

2. The parent career forum led the inspirational multi-agency outcomes training for professionals across all of our partners. This has directly resulted in an improvement in outcomes for Children and Young People.

3. The co-production of the Short Breaks offer has led to a sensible way forward for the joint commissioning of Short Breaks. The parent carer forum rescued this from the jaws of defeat due to poor practice.”

**Colin Foster, Director of Children’s Services Bedford Borough**

“LPCF’s involvement in the Special School provision review and subsequent strategy has been invaluable. The forum has represented parents and carers views, helping to build a sustainable and lasting strategy that meets the needs of the young people with Special Educational Needs in Lincolnshire. The support and input from LPCF in the Willoughby School parents and carers meeting was hugely valued and appreciated by all who attended.”

**Special School Head Teacher, Lincolnshire**

## Our national work

At a national level, the key message that we have delivered to government is that the aspirations of the SEND reforms have not yet been delivered.

### *The impact of resource constraints*

The last year has seen an increase in concerns from forums that their local areas cannot deliver the legal requirements of the Children and Families Act with existing, constrained resources. An increase in the number of children and young people with SEND, combined with new entitlements mean that many forums report that local areas are struggling. The changes in the way in which the dedicated schools grant and the high needs funding block can be used have limited the flexibility of local authorities to switch funds between budgets. Finally, the failure of many areas to make meaningful progress with joint commissioning has amplified this situation.

In our meetings with Ministers and Officials we have continued to share our view that these are the “right

reforms in the wrong environment.” We took the step of putting our name to the Special Educational Consortium position statement highlighting the pressures on the high needs funding block. We have emphasised to ministers at the Department for Education and the Department for Health and Social Care the need for them to lead, model and enforce the need for joint working and commissioning across the sector.

### *The quality of Education Health and Care plans*

The quality of Education Health and Care plans remains a key focus for the NNPCF. Many forums have reported that quality has been sacrificed to meet the conversion deadline of March 2018. Forums have also reported that Local Authorities are struggling with the ongoing requirements to review plans. This has been recognised as a key area for improvement by the Department for Education.



*“It is a privilege to be a part of the partnership between NHS England and the National Network of Parent and Carer Forums. Together we have demonstrated parity of expertise and we continue to be encouraged by NNPCF’s invaluable contribution to the health and wellbeing of children and young people with Special Educational Needs and Disabilities.*

*“For the first time this year we have jointly discussed successes, issues and concerns with health and education ministerial colleagues. This has been an important achievement in response to a request made at last year’s conference. This is true evidence of our ongoing commitment to co-production and partnership working. At the same time, we are pleased to see growing evidence of improvements in health engaging in the SEND agenda.”*

**Heather Caudle**

Director of Nursing – Improvement (NHS England)

“Over the last year, the collaborative work with the LPCF has been invaluable. The strategic review of specialist provision in the county has been strengthened as a direct result of the constructive challenge and knowledge provided by the forum, ensuring that future plans have been influenced by families’ views and perspectives.

“The addition of a LPCF representative to the decision-making process around Education, Health and Care Plans has proven to be a real asset and the work of the forum in supporting the recently established Young People’s Forum ensures that the SEND partnership is benefitting more and more from the voice of young people and their families.”

**Children’s Services Manager,  
Lincolnshire County Council**

**90%**

**of forums reported they were aware of illegal or unofficial exclusion practices in their local area.**

Exclusions stat – NNPCF survey of parent carer forums February 2018

**At 31%**

**the disability employment gap remains high.**

Disability employment gap  
– Office of National Statistics May 2018

### ***The experiences of children with SEND in mainstream schools***

Our member forums have reported continuing issues for children with SEND in mainstream schools. The achievement gap for pupils with SEND, the drift towards special schools and the rate of exclusions for pupils with SEND all cause alarm. We raised these concerns to the Department for Education and have been pleased to see the experiences of children with SEND in mainstream schools emerge as a priority area.

We are participating in the review of school exclusions being conducted by Edward Timpson. The findings of our survey in February that showed that over 90% of Parent Carer Forums were aware of illegal or “unofficial” exclusions fed into providing key evidence for our concerns.

### ***Preparing for Adulthood***

Families still describe the point at which their young person leaves education as a cliff edge. They report poorly joined up transitions between Children’s and Adult Services, a lack of provision of key services such as housing and a struggle to find employment, training or voluntary work. The disability employment gap remains high at 31% and too many of our young people end up as NEETs (Not in Education, Employment or Training).

We have been working with the Department for Work and Pensions to articulate the challenges that young people with SEND face in order to remove some of the barriers in their way.

## Accountability of the sector

The NNPCF has continued to work to improve the accountability of the sector through the inspection and tribunal processes.

Ofsted and the Care Quality Commission inspect education and care settings, and jointly inspect local areas to see how well they fulfil their responsibilities for children and young people with SEND following the implementation of the Children and Families Act 2014. In 2017-18 we continued to ask for an extension of the current round of local area SEND inspections and for areas with a Written Statement of Action to be re-inspected. Both of these themes were picked up by the Secretary of State for Education in his first speech to the sector.

We welcomed the introduction of the national single route of redress trial, which extends the powers of the SEND tribunal to make non-binding recommendations on Health and Social Care providers.

During 2017-18 the regime of local area inspections continued at a pace. Whilst Parent Carer Forums are not a part of the inspection, the inspectors did comment on the role that Parent Carer Forums play in their local areas.

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### Some examples from inspections in 2017-18 include:

“Information officers, employed by the Wiltshire Parent Carer Council (WPCC), work tirelessly to support parents and carers in navigating the local offer and providing individual information, guidance and support to families. They provide informative weekly newsletters, information events and regular workshops which are well attended. Often facilitated by the WPCC, the local area has been very active, consulting with parents and carers across the county and responding to feedback through regular ‘You said, we did’ reports.”

**Wiltshire, January 2018**

“The parent carer forum in the local area has significant insight into what is important to parents in Sutton. As a result, parents and providers were overwhelmingly positive about the support they provide.”

**Sutton, January 2018**

“Parents and carers make a strong and influential contribution to implementing the disability and special educational needs reforms in Wakefield. They are passionate about working with local area leaders to make things better for children, young people and families. Parents and carers receive high-quality support from ‘Team Wakefield’, the parents and carers forum.”

**Wakefield, June 2017**

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“Parents and leaders value ‘HIP’, the local parent network, as a source of information and support. Provider leaders appreciate the attendance of HIP members at their forum meetings. Parents say that the network is invaluable in helping them navigate information and helps them feel less isolated.”

**Hackney, November 2017**

“The Parent and Carer Forum has become increasingly involved in contributing to decisions taken by the local authority to improve provision for children and young people who have special educational needs and/or disabilities. For example, forum members have recently helped to appoint an additional special educational needs case worker.”

**Rutland, July 2017**

“The members of the Parent Carer Forum (PCF) are skilled, knowledgeable and well respected. They have been actively championing the rights of children, young people and their families, consistently raising their ongoing concerns about the provision in Bedford Borough.”

**Bedford, February 2018**

“The PCF is a key partner in driving through the reforms in the local area. It has demonstrated that it plays an effective role in co-producing services with local area leaders, while representing the views of parents and carers robustly and with compassion. PCF leaders are keen to extend opportunities for co-production with service leaders and to do more to support and challenge leaders to improve services for families, particularly in areas of weakness.”

**West Sussex, February 2018**



*“Working with the parent carer forum at national and local levels in the continuous development of the SEND programme and in local areas as part of the inspections has been instrumental in ensuring the voice of children, young people, their parents and carers remain an influential and important partner in our work. Representatives of the PCF continue to provide training to inspectors to enrich their knowledge and reinforce the impact of SEND in families.”*

**Jonathan Jones** (Ofsted)  
and **Lea Pickerill** (Care Quality Commission)

## Consultations

The NNPCF’s core function is to be the national voice of Parent Carer Forums. Responding to national consultations and Calls for Evidence is therefore an important role for the NNPCF. In doing so, the Steering Group draws upon the experiences of parent carers from local forums and regional network meetings, working together to effect policy and service improvement at a local, regional and national level through participation and co-production.

**Over the course of the year, we worked with our membership to respond to 12 consultations.**

Social Work England: Consultation on Secondary Legislative Framework

Children and Young People Mental Health Green Paper

Department of Transport Blue Badge Eligibility Consultation

Working Together to Safeguard Children: Changes to Statutory Guidance

Learning Disability and Challenging Behaviour Draft Guidelines

Reformed Functional Skills Mathematics and English Subject Content NNPCF

Returning to Work after Time out for Caring

NNPCF Consultation Response to the London Mayor’s Vision for London

London Assembly SEND Investigation

Rochford Review Recommendations

Exclusions Guidance

Child Abuse and Neglect Draft Guidelines

All responses are published on the NNPCF website <http://www.nnpcf.org.uk/get-involved/consultations/>

## Communications

We have been working hard to improve our communication capability both to our member forums and to the outside world.

We have increased the frequency of updates of our activity to our website and we ensure that we update our members and the SEND community on the work we are doing. Our posts announcing the review in school exclusions, the single route of redress national trial and our sign posting to Council for Disabled Children (CDC) Annual Review Guidance were amongst our most popular during the year.

Social media networks play a very important part in what we do. We use it to inform one another, our forums and the parents within them. Our posts are often shared widely and the opportunities this gives for our members to have their voice with national consultations as well as our own.

# NNPCF COMMUNICATIONS

## Informing our communities

As the national voice of parent carer forums the NNPCF shares your views and experiences with our national partners. Whilst this is a crucial part of our role, it is equally important that we feedback to our member forums what we are saying on your behalf and what we are hearing in response.

### ACTIVITIES

In 2017-2018 the NNPCF Steering Group & National Representatives Team participated in a variety of activities ranging from workshops, meetings, and events, to training days, presentations, and working groups.



### WEBSITE UPDATES

Over the year we have produced 32 updates that have been shared via our website. These detail our activities as a network and key information we want to share with our members.



### 4,533 LIKES 4,480 FOLLOWERS



### 2,958 FOLLOWERS 1,182 FOLLOWING



## SOCIAL MEDIA

Our social media channels are an important vehicle for us to share information, key messages, and updates with our member Parent Carer Forums and their wider communities. This year our social media activity has increased significantly with us sharing more information about our work and that of our partners and members.

## National Network of Parent Carer Forums – AGM and Annual Conference 2017

Our conference in Manchester in 2017 was a huge success. For the first time we held the event over two days and we had a great response from our membership with 245 attendees, representing over 100 forums.

Some of the highlights from the two days included:

- A series of workshops on topics chosen by our membership that we used to inform our priorities and talking points
- A question and answer panel with representatives from the Department for Education, Department for Health and NHS England.
- A key note from Nigel Thompson from the Care Quality Commission about learnings from local area inspections



The conference also marked some key decisions for the NNPCF – we adopted a new vision and mission that better reflects what we want to achieve after the end of the implementation period of the Children and Families Act and we voted to set up a new Community Interest Company for the NNPCF.

As ever, we could not have achieved what we did without the help and support of our partners Contact and our sponsors, the Seashell Trust.

# Parent Carer Participation in 2016-17

**contact**

For families with disabled children

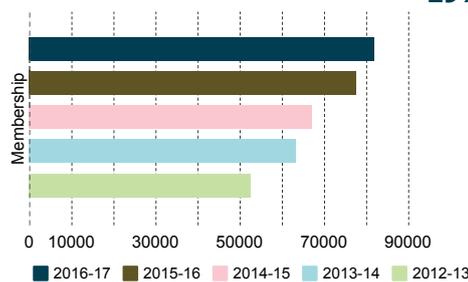
Freephone Helpline 0808 808 3555  
helpline@contact.org.uk  
www.contact.org.uk



contactfamilies

## Reach is increasing...

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



## Stronger governance

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

There is a clear, positive, year on year trend towards more Forums becoming constituted organisations.



## But engagement is more challenging

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

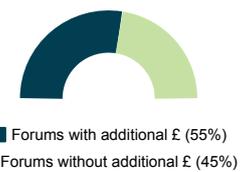
This suggests the work of representation and running Forums is falling on fewer shoulders (proportionately) every year.



## Finance and sustainability

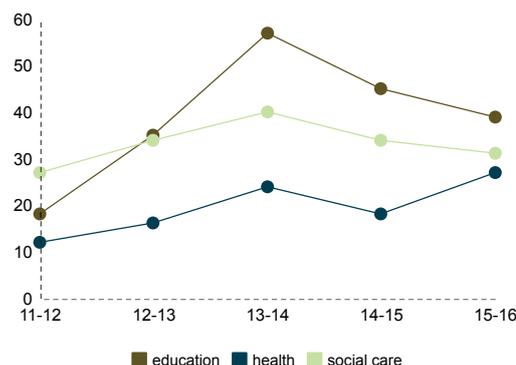
55% of Forums receive some additional income, but 45% still operate on the DfE grant alone. These proportions have remained similar since 2012.

In 2016-17 we saw a small but significant increase in the numbers of areas where the Local Authority and health partners co-fund Forums - rising to 11, from 2 in 2015-16.



## 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.

To read the whole report please visit [www.contact.org.uk/parent-carer-participation](http://www.contact.org.uk/parent-carer-participation)

# Regional Parent Carer Forum Networks

The regional networks play a key role in providing peer support and sharing stories about what works and what doesn't.

The work done in the East of England in identifying, contacting and talking to seldom heard groups has been shared nationally through a Contact webinar, equipping forums to engage with groups (such as the traveller community) who haven't had much of a voice before.

The North East has been leading the way with its work on the Transforming Care agenda. It has led to greater awareness of the forums and parent carer participation. There is a multi-agency aim to establish communication across all agencies to promote and understanding of the Transforming Care agenda and reduce gaps in service provision. There is a sound framework in place now and key activities for forums to potentially develop.

The London Strategic Managers Network, which is attended by the Strategic Local Authority and Clinical Commissioning Group (CCG) leads within London, has been particularly important to parent participation, through their commitment to co-production with parent carer forum representatives. It provides a model of best practice for co-production and provides evidence as to what works. The London region have enjoyed rich and informed debates about best practice in Health, Social Care, Outcomes, quality EHCPs and Co-production.

Peer to peer support is the most used category on our closed Facebook group. Helping each other is extremely important to us and if something is working well in another forum, there is no point re-inventing the wheel! Our social media support groups have had lively debates and information sharing on topics as wide ranging as illegal practices in issuing EHCPs in the run up to the transfer deadline to arranging to meet for tea and cake after a conference.

# Regional Reports

Our local and regional forums are of vital importance to the NNPCF, and supporting their ongoing development remains a priority.

The following reports describe the work that has been taking place in each of the nine regions.

## Regional steering group member for North East & Cumbria

**Maureen Morris**

During this year, there has been a real sense that the region is starting to see itself as a whole, with lots of cross boundary contact and increased activity on the regional Facebook pages. Several forums in the region have had changes in their Steering Group membership, which has led to an increased desire to engage with each other across the network.



More Parent Carer Forums have managed to secure additional funding or have Local Authority support, which has eased the pressure on forums and provides more opportunities for increased engagement. Two forums decided to move towards independence from their host organisations, and a new forum has been set up in Redcar & Cleveland, following the demise of the previous forum. It has therefore been a period that has seen some change in the region, but one that has led to a renewed focus and enthusiasm.

The regional Cluster groups are working well, with steady attendance at the regular cluster meetings arranged during the year. Support was put in place to support the South cluster, as they were without a Co-Chair for a period of time. Additionally, a lot of work has taken place regionally:

- In January, forums benefited from regional training provided by Irwin Mitchell. The ‘Legally Speaking’ session looked at what must by law be in EHC plans and what should not be included.
- Thanks to a discretionary grant, we ran our 3rd Regional Conference in March, the focus of which was Health, Co-Production and Moving Forward. The conference was very well attended and received positive feedback. Topics discussed and presented during the day included Transforming Care, NHS England, Contact, Hate Crime and the Regional Peer Network. Attendees also undertook a table exercise, where attendees were asked identify in their local areas:
  - What could be better?
  - What is going along okay?
  - What is working well?

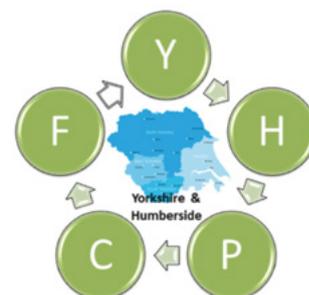
Some common concerns were highlighted, including inconsistent EHCPs, schools not being inclusive enough, concern about being seen as a box-ticking exercise rather than real co-production being introduced, and forum capacity and commitment. However, it was also recognised that forums are going strength to strength, there are new CAMHS pathways, relationships with SENDIASS are positive, and there are opportunities for parent carer engagement in strategic work. We are particularly



## Regional steering group member for Yorkshire & Humber

**Julie Bruce**

This past year has been a period of great change within our area, as we said goodbye and thank you to Fiona Beard for her sterling service to the region over the years.



Fiona led us from the start with passion, enthusiasm and gritty determination to put parent carer participation at the top of the agenda constantly, yet always remained grounded and in touch with everyone she represented at National level.

Fiona was a sensationally sparkly act to follow but having been Regional Co-chair and having worked closely with Fiona, I have now taken on the Regional Rep role and made the first meeting with the Minister memorable! I know that the region is firmly behind me and supporting me as I develop the role and further increase the profile of the region. Thank you to everyone for their support!

Our main challenges as a region this year have been lack of health engagement and poor EHC Plans. Therefore, in the year ahead there will be a regional focus on promoting the need for high quality EHC Plans, and we will be looking at offering parent carers opportunities to attend workshops to get the most out of the EHC assessment process. We are also seeking to increase engagement with Health but locally and regionally, at both service and strategic levels. We will also be encouraging work around Preparing for Adulthood (PfA), with a view to getting Children's and Adult Social Care working together better for our children and young people.

grateful to everyone who stepped up and volunteered their time to assist with the planning and organisation of the conference. Thank you!

- The Transforming Care work in the region has led to greater awareness of the forums and parent carer participation. There is a multi-agency aim to establish communication across all agencies to promote and understanding of the Transforming Care agenda and reduce gaps in service provision. There is a sound framework in place now and key activities for forums to potentially develop.
- We have undertaken some peer moderation, where forums and Local Authorities worked together looking at different areas' EHC plans Local Offers. This was well received.

Forums have reported that engagement with health is increasing, though this is at very different rates across the region. They have also, unfortunately, highlighted squeezes on Short Breaks funding within the region.

We had a good attendance at the NNPCF AGM and National Conference in the Autumn, and the forums who attended were very enthusiastic and have encouraged the forums who did not attend to try to go next year.

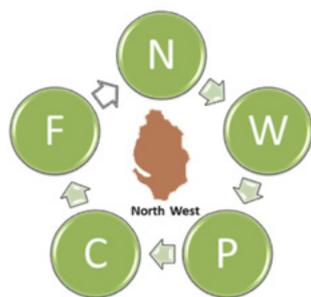
I would like to thank everyone involved with Parent Carer Forums in this region for all their hard work and enthusiasm during this year. I am confident we will become an even stronger region in the coming year, as all forums work together more effectively and continue to share their ideas and best practice.

Finally, I would like to thank Jayne Fitzgerald for being Regional Co-chair with me and I would like to welcome Sara Smithson to the role of Chairperson for the coming year – we all wish her the very best of luck!

## Regional steering group member for North West

**Kath Bromfield**

This year has brought many changes to the regional structure within the north west, including my taking over the role of steering group member in September 2017.



Prior to this a development day was held within the region, organised by the previous regional steering group to add shape and direction to the way we met as a region. On the day many things were decided including a report detailing how we had agreed to move forward. Following this our regional Contact advisor, Kate Hurn, and myself took the report and tried to put things in to action. The focus was on ensuring everybody had time to comment and vote on the changes before they were implemented. As a consequence of this we now have a governance structure regionally, and representatives that have been elected by the whole region.

I am inspired and filled with confidence by the conversations and passion from forums within the region. Change is never easy, yet we have a commitment to try to engage with a wider group of forums and their representatives. We have agreed to hold three regional meetings a year, and three workshops.

As we see nationally some forums within the North West are facing the strains that running a forum can pose. We are working hard to make the ways

we feed up to the NNPCF, and how we feed down, clearer. This year saw Gail Walsh from Contact, and Cath Hitchin from the Department of Education, attend a regional meeting which was well received. Discussions on the day highlighted concerns around the Local Area Inspections and all that entails, and the changes to the IS funding. Both Gail and Cath gave some insight into these issues and allowed forums to feel that they were more prepared for the inspections.

The AGM and Conference in Manchester was well attended by the region and we were proud to host it in our area. Feedback from the Conference was positive and parent reps felt engaged in the process. Following on from the development day, we have tried to hold regional meetings in different places, and this has resulted in different forums attending and a number of people from each forum attending some meetings. The regional reps have met a number of times and we now have a plan of meetings for the year.

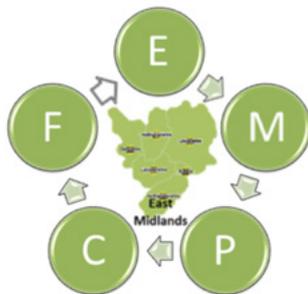
The developments within Greater Manchester and the devolution hold both exciting and anxious feelings for forums, we are constantly working on ways that the 10 forums can contribute to the exciting conversations that are taking place. Many forums have fed back that they are pleased with the development the region has made within 2017-18, and we look forward to working together in 2018-19 to ensure that forums feel supported and engaged as a region.

As my first year in the steering group role comes to a close, I would like to thank all the forums, the regional representatives and Kate for their continued support and ability to work together on behalf of the region.

## Regional steering group member for East Midlands

### Dave Nutting

After a short sabbatical, I am once again the NNPCF Regional Representative for the East Midlands. I would like to thank Catherine Wood, from Contact, and the forums in the region for holding the fort in my absence. I am pleased to be back, and to able to bring you this report of regional activity for the year.



During the year, forums in the region have been engaged in a wide range of engagement opportunities, examples of which include:

- Derbyshire Parent Carer Voice have been commissioned to consult with parent/carers and workers on their views of the strengths and disadvantages of foster and residential care as a placement option for children with additional needs. They got involved with visiting support groups, telephoning parent carers and collecting views using surveys electronically and on paper.
- Northants Parent Forum Group worked closely with Autism Commissioners to develop an Autism Strategy for Northamptonshire
- Lincolnshire Parent Carer Forum were invited to attend pre-school SENCO briefings around the County and gave a presentation about the forum and its remit to Pre-school SENCOs. This was a brilliant opportunity to engage with pre-school settings in the hope that they could reach more parents at an earlier stage in their parenting journey.

- Nottinghamshire Parent Carer Forum delivered their first conference as an independent group, with their Steering Group team organising it. They had a speaker to run the morning session, which was an interactive session about dealing with meetings, which resulted in a 'Top Tips for Meetings' document that has now been sent out to all members. This was followed up in the afternoon with a 'Question Time' session asking questions of the experts on the panel.

The East Midlands region continues to enjoy good engagement and information sharing with the regional leads. The Peer Review process, which has now been in place for two years, is also now starting to take shape, with training taking place.

**"The contribution made by the Lincolnshire Parent Carer Forum to the review and consultation process for county wide reforms to specialist provision has been excellent. Their impartial advocacy for the voice of all stakeholder parents and carers has ensured a thorough opportunity has been afforded to influence and challenge plans for SEND provision across Lincolnshire."**

**Head Teacher of Special School**

In March 2018, a regional event took place, based around the theme of Preparing for Adulthood. Ellen Atkinson and Pat Bullen supported the event with a general presentation before delegates could select workshop topics of interest. The choice of workshops included supported internships, the working health programme, assistive technology, and Wills, Trusts, Deputyships. The event was supported by a market place where 19 providers showcased their services in the East Midlands region to parent carers attending. Despite challenging weather conditions (snow and ice the weekend prior)

the event was attended by 47 parent carers and professionals, and feedback has been very positive. This event not only brought the region closer together, but also provided in depth information and networking opportunities to the parent carers who attended.

This is particularly important for the East Midlands region, as I am keen to support closer working across the region and between forums. We are about to go back to being a constituted group once more, with a new constitution. This would hopefully lead to greater regional working. As many regions are experiencing, some forums in the East Midlands have had capacity issues, whilst others have been focussing on developing their structures and tackling organisational challenges. I hope that during the next year forums across the East Midlands region will be able to pull together and support each other in tackling the challenges that are being faced. I would like to thank the forums in the East Midlands region for all of their hard work this year. I look forward to working closely with you all in the year ahead, to build on the work that has taken place in 2017/18.

## Regional steering group member for West Midlands

**Zara Bowden**

2017-18 has seen a number of West Midlands forums celebrating milestone birthdays. During this year, Shropshire, Birmingham, Telford & Wrekin, Walsall, Wolverhampton, and Herefordshire have all celebrated having an operational Parent Carer Forum for ten years or more. Some of these forums may have been reinvigorated or reimagined over the years, however they have consistently been there for their communities with a core group steering the forum.



All forums this year have taken time to reflect on the progress made during the implementation phase of the SEND Reforms. Some have identified significant steps forward and examples of positive impact on their local areas as a result of the changes the SEND Reforms have brought about:

- Shropshire Parent and Carers Council have seen the creation of a dedicated transitions team within social care who will work with young people aged 18-25 on their pathway to independent living and employment, and the planning of a September 2018 launch for a funded Graduated Support Pathway within schools as part of their SEN support offer.
- Coventry One Voice have developed improved relationships with Health partners locally, this has led to an increased number of participation opportunities in Health service development.
- Walsall held parent carer representative training, attracting new parents from within the community to support the Parent Carer Forum in sharing

families experiences more effectively as they can attend more participation opportunities locally.

- Solihull Parent Carer Forum were successful in securing a seat on the 'Ed SEND Board' which has given them a greater platform for identifying coproduction opportunities, as well as holding a 're-launch' event for the forum towards the end of March.
- Telford and Wrekin's Parents Opening Doors held their 'Picnic in the Park' which provided local families the opportunity to meet and enjoy outdoor activities together.

We have had continued growth and development within our regional network too. A regional Preparing for Adulthood (PFA) event took place at the end of March, hosted by Shropshire, which was well received. The event focused on writing good PFA outcomes, the importance of ongoing planning, and learning more about supported internships.

We also held a Regional Training Day, looking at how forums in the West Midlands can explore their participation and develop it further, ensuring that it is meaningful and that forum representatives can feel confident in saying no to tokenistic participation.

As the Regional Steering Group member, I was particularly pleased to see we had consistent regional engagement from the majority of our active forums, with only three forums struggling to join us frequently. As a region we are all very much aware of the challenges some of our smaller forums have (smaller in number of active steering group members) in being able to spread themselves across local and regional activity.

As a region, we recognised continuing challenges in the following areas:

- Transport at a local level is consistently difficult, especially with a lack of recognition from transport teams about the importance of coproducing solutions with SEND families from the start. This has led to some worrying reports of families being left without safe, adequate, or appropriately trained transport services available to them.
- Health engagement continues to be limited to a selection of high-level boards, with few Parent Carer Forums being invited to co-produce at an operational level. Many forums are still only invited to engage through the traditional patient participation pathways, which we have reported regularly to be inaccessible and inappropriate for Parent Carer Forum representatives to participate in, due to their lack of focus on children's or young adult's services, plus they are often held at difficult times of the day.
- Social Care engagement is improving but still has a way to go. Forums report there is a reluctance to see SEND as part of the wider Social Care remit and that getting involved in the development of early intervention services is still challenging. We are seeing great engagement in Short Breaks development and many Disabled Childrens Teams are welcoming co-production with their local forums. However, we are still yet to see a significant improvement in Adult Social Care teams and non-assessed social care services at the more targeted, and less specialist, levels.
- Regional partnership working is still a work in progress, this year we have identified that communication is the most challenging element, with forums highlighting this as a priority area for next year alongside regional Health and Social Care partnerships needing further development.

Our regional priorities in the year ahead include CAMHS, further engagement with Health, the sustainability and development of our member Parent Carer Forums, and of course EHCPs and Annual Reviews.

## Regional steering group member for East of England

**Mrunal Sisodia**

It has been another busy and successful year for the East of England region of parent carer forums. Both as a region and as individual forums we have faced some challenges, but we have also enjoyed some inspiring successes.



At the end of the year, Kulwinder, our Regional Chair, invited member forums to reflect on what the region meant to them. Here are some of the themes received in feedback from our member forums:

- Sharing information and best practice
- Providing peer support between forums
- Influencing national policy positions through the NNPCF
- Sharing expertise and research (e.g. GDPR)
- Providing a heads up about developing issues
- Hearing from speakers and guests (DFE, Ofsted, NHSE)
- Direct access to colleagues from Contact

The two successful workshops we held during the year provide excellent examples of this in action. Luton ran a session on how to work with Seldom Heard groups that was later turned into a national Contact webinar, and Peterborough led a session on Parent Carer Forum funding and raising income, which our members found very valuable.

We continue to have an excellent relationship with the Peer Network, who consistently talk of a four-way partnership between parents, education,



health and social care. Our Regional Conference in March was very successful, with Parent Carer Forums in attendance, speaking and leading some sessions. As a region, we were invited to share some of our insights in a 'developing your region' webinar that was well received by our other regional colleagues.

The strength of the region is built on the strengths of its member forums, and individual forums in the region have undertaken some great work making a real difference to children and families in their localities.

There are too many achievements to list individually, however the types of activities forums have been doing include:

- Challenging or stopping controversial or illegal practices
- Developing and delivering training to improve the knowledge and capacity of services
- Partnering with education, health and social care to develop innovative and effective services
- Pioneering techniques to empower forgotten or seldom heard sections of the community.

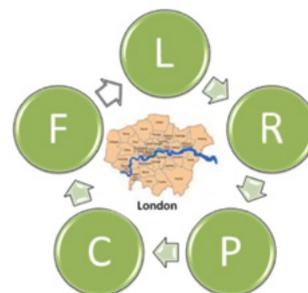
However, there remains much to be done and all of our forums depend upon the hard work and determination of their members. Capacity and resilience remain key concerns and as a region we are exploring ways in which we can support each other.

And finally, I am delighted to report that Essex Family Forum launched in February, after almost 18 months of hiatus. They have a new organisation, a new energy and a new sense of purpose. Another example of the teamwork across the region and thank you to the other forums in the region, and to Contact, who helped support them to get going.

## Regional steering group members for London

**Kay Moore** and **Fazilla Amide**

London is the largest region in terms of Local Authority areas and population and consists of 32 Parent Carer Forums. The London Region has two NNPCF Steering Group



representatives who cover 3 cluster groups, North East, North West and South.

Termly cluster meetings are held, which are hosted by different forums. These meetings are very important to the forums as they offer opportunities for shared learning, peer to peer support and two-way communication with the NNPCF Steering Group. The London Facebook group also enables forums to share practice, ideas and views, virtually.

During this year, forums across London have continued to work very hard to influence the implementation of the SEND reforms with Local

The key to parent participation for us in Camden is getting the LA more involved. We have recently held a parents' Feedback Day and a Response meeting with high level LA professionals showing their intention to engage with parents more meaningfully. The more we can show parents that their feedback is not only listened to but acted upon the greater participation there will be.

**Camden**

Authorities and CCGs. Since April 2017, nine forums have been involved in local SEND inspections and a number of these inspections have highlighted the excellent work the forums have been undertaking, recognising the insight forums have into local needs, their ability to influence strategic decision making and the improved relationships between parents and professionals. However, as elsewhere in the country, three of the London Local Area Inspections have resulted in Written Statements of Action, partly due to the lack of meaningful engagement with their local Parent Carer Forums or lack of joint strategic working.

The key to parent participation for us in Camden is getting the LA more involved. We have recently held a parents' Feedback Day and a Response meeting with high level LA professionals showing their intention to engage with parents more meaningfully. The more we can show parents that their feedback is not only listened to but acted upon the greater participation there will be. *Camden*

At a regional level, much of the last year in London has been spent continuing to develop regional representation through the London Strategic Managers Network, the London SEND Regional Lead Programme and our strong relationship with the London Councils.

The London Strategic Managers Network, which is attended by the Strategic Local Authority and CCG leads within London, has been particularly important to parent participation, through their

commitment to co-production with parent carer forum representatives from each of the three clusters, which provides a model of best practice for co-production, and provides evidence as to what works. We have enjoyed rich and informed debates about best practice in Health, Social Care, Outcomes, quality EHCPs and Co-production.



One of the London NNPCF reps is also a member of the SEND Regional Lead for London Steering Group, which jointly plans the London Training and Peer Support programme across all Local Areas. This SEND Regional programme has enabled positive peer to peer support to be extended beyond the cluster meetings, through the regional workshops and events which continue to be well supported by forums across London.

The London Region also submitted evidence to inform the London Assembly Education Panel's Investigation into Special Educational Needs and Disability (SEND) provision in London and responded to the Mayor's Vision for London consultation.

A further highlight in the year was the publication of the London Region's *"Parent Participation, Co-production and Health: learning with NHS England on SEND, Transforming Care and Healthy London Partnership event report."* This report set out the top three priorities for Parent Carer Forums in London:

- 1 Demonstrable legal compliance within SEND system (processes and outcomes)**
- 2 Greater consistency and accountability in Health at all levels**
- 3 Understanding the needs of families better**

Parent Carer Forums in London wanted the identified priorities to inform work and planning in London with Health and the wider SEND community, including planning for a London regional Health event, which took place on 8 June 2017.

Finally, we want to acknowledge the hard work and commitment of the London forums over the past year. We have been striving to develop a region which supports each other, and which helps forums manage a complex array of issues with capacity constraints.

We would also like to extend a big thank you to Mary Busk, who stepped down as the NNPCF Steering Group member for London this year. Mary has been the longest serving member of the NNPCF and will be greatly missed. We would also like to congratulate the City of London forum on setting up this year; we look forward to working with you in the year ahead.

## Regional steering group member for South East

**Lara Roberts**

I was delighted to be re-appointed as the Regional Representative for the South East this year, so that I can continue to support local forums to develop parent carer participation, both in their local areas and at a regional level. This year has seen some new forums flourishing, and some older, more established forums continuing to grow and develop participation locally.



Our regional cluster meetings give Parent Carer Forums the opportunity to come together, to update each other on progress and to share concerns and ideas. We hold meetings in the North and South Clusters, and also come together once a year. During the last year, we took the opportunity to review our Regional Network cluster meeting structure, to ensure that it continues to be suitable for the region's forums. The structure is only a year old in its current format, so we are seeking to improve it all the time.

Our regional cluster meetings have included attendance from Daniel Evans (Assistant Director of SEND, DfE) and Andre Imich (SEN and Disability Professional Adviser, DfE), where they heard directly from Forums around their shared their experience around Transfers and Regional Joint commissioning.

At our last Regional South East Gathering, where the majority of the South East region comes together, we developed Peer to Peer Top Tips in Engagement with Health, Preparing for Adulthood and SEND Local Area Inspections that could be shared around the region.

Not only have we been working together as a region more closely via our regional network cluster groups, but also now as the SE19 Strategic Co-production Partnership Group (SE19 is the umbrella term for the 19 Local areas in the South East). The purpose of the group is to champion and demonstrate co-production and provide a platform for discussion around co-production at a regional and national level. It also offers opportunities to share progress, ideas, challenges and solutions around how co-production is working at a strategic and operational level in the South East region and to use the 'Co-production Lens' across service design and development and test out the impact. Members of this partnership group are Local Authorities and Parent Carer Forums, but the group also seeks to engage with wider groups from local area such as Health, Social care and Young People. The group informs ideas and thoughts that can be fed back to the SE19 Leadership Steering Group.

And finally, as a region we developed Leadership training. This Training is written and will be delivered by the region to support leaders to develop their own leadership skills in the local area.

I would like to thank everyone involved with Parent Carer Forums in the South East region for all of their hard work and commitment this year. I am looking forward to working with you all in the year ahead.

## Regional steering group member for South West

**Tina Emery**

2017-18 has brought many changes in the region, including a change in Regional Representative, following Doug Morris stepping down after being in the role almost five years. This led to my appointment as the new Regional Representative in October 2017.



The focus within the region this year, has been to develop more unity and to make the region stronger. It is an exciting time, as the Parent Carer Forums in the region are all working and communicating together, and learning from each other, which is especially important as there are some fledgling forums in the South West, and other forums who have had steering group changes. Additionally, more and more forums are reviewing their own governance and are considering becoming Community Interest Companies (CICs) or Charities – so it has been, and continues to be, an interesting time for the region and the forums within it.

Unfortunately, on occasion, Cluster meeting attendance has been affected by the increased workload because of Local Area SEND Inspections. However, forums continue to engage with each other outside of these meetings, following the successful launch of our regional Facebook group. We have been particularly delighted to see that the Isles of Scilly forum have been able to attend more regional cluster meetings and attended the AGM in Manchester; they felt this was particularly important

for their development and to build relationships with other parent carers and their forums, on both a regional and national scale.

More reps are attending regional meetings than ever before, which is making the region even more resilient. This is in part thanks to our Regional Admin, based within Somerset Parent Carer Forum and our Regional Contact Advisor, Sue Mennear. It is hoped that this attendance will increase further as time goes on, which should lead to greater confidence and more information being shared.

**“The information events that Cornwall Parent Carer Council hold are invaluable, they are informative and helpful for support and guidance, the newsletters they produce, give me information and choice, when I have no idea in the world of SEND”**

**Cornwall**

This year also saw us being more engaged with our regional SEND NHS England leads. We were delighted to welcome, for the first time, a regional lead at our Regional event in February 2017. He provided an insight to their role and explained how they can hold CCGs to account for parental engagement, and his attendance was particularly well received.

All forums enjoyed the Regional event, however a theme that became very apparent during the day was forum anxieties around the Local Area Inspections. We were fortunate, however, to have a forum whose Local Authority had only been inspected the week before, so they were able to provide an updated view of what to expect during a Local Authority inspection, and what information forums should have ready.

We have seen an increase in parents wanting to campaigning against cuts and changes to services in some areas. As a result, South West forums have been sharing ideas of how best to engage with campaigning organisations, to help shape services. The work of one of our forums is being used as a good example by Contact who are supporting forums in this regard.

Finally, I would like to take this opportunity to thank Ruth, Sue and all the South West Parent Carer Forums for all your hard work, your insight and your resilience. We have had some joy and some hard work to do along the way, but I feel confident that together we will have an amazing 2018-19! We know that there are changes abound for 2018-19 for some forums, with the creation of two unitary authorities in Dorset, which will impact on the forums in Bournemouth, Poole and Dorset. We recognise the uncertainty that is going to bring but know with the support available from this fab region, they will be able to achieve whatever the affected forums and parents decide they want to do.

# Ten Years of Funded Parent Participation

The Steering Group recently spent some time thinking about this anniversary and reflecting on what ten years of funded parent participation means to our member forums and the wider world of SEND and participation.

We are aware that there are some forums who have been around for longer than 10 years, who are the true pioneers in this arena and there are some areas where the forum has been through two or three incarnations as people and circumstances change. However, the fundamental principle of parent and carers coming together to improve outcomes for their children and young people lies at the heart of all of our work.

We have had the unwavering support of Contact for the last 8 years and that plays a large part in the organisation we have become and what we aspire to become in the future.

We know that we do not stand alone when we are voicing the issues affecting our families as we are often another voice amongst the range of voluntary sector organisations and campaigning groups that support our families. However, what we bring and always have done is the collective voice of our membership. We are now, and always have been, parent carers speaking for parent carers.

We continue to grow and evolve as the issues demand and need arises. We salute you all, both the giants of the early years of participation and those who stand waiting in the wings to take up the mantle in the future.





# Looking Ahead...

Every year of the NNPCF has brought its own unique challenges and opportunities and the coming years will be no different. No matter what, we will remain true to our principles of co-production and we promise that we will continue to:

- Listen and hear what you are telling us, to seek solutions with strategic partners and government on the issues that affect the lives of you and your members children and young people with SEND.
- Consult and co-produce with you on those matters of interest and concern to our member forums, to ensure the best outcomes for all our children and young people.

We look forward to working with you in the coming year.

**Maureen Morris** and **Mrunal Sisodia**

Co-Chairs, NNPCF 2017-2018

# Meet your current Steering Group

## **Dave Nutting East Midlands**

Dave has been involved in parent carer participation since the start of the Aiming High agenda back in 2007 and was part of the select team that co-produced the successful plan for the proposed development of a National Network of Parent Carer Forums to the DfE for funding.

Dave was a founder member and Chair of his area and regional forums and is currently the Secretary of Leicester City PCF.

Dave has a son with multiple complexities, including Autism, ADHD and Epilepsy.

## **Fazilla Amide London**

Fazilla was elected to the steering group in 2017. She has a background in HR, Training, and Change Management that bring with her 20 years of experience in working with global organisations.

Fazilla has a son with complex health needs and ASD. She is currently chair of her local parent carer forum in Enfield.

## **Julie Bruce Yorkshire & Humber**

Julie is coordinator of her local forum as well as chair of her local Healthwatch. She has a background in welfare services, and brings with her extensive knowledge, which she continues to develop after studying for her MA & PhD in Social Policy. Her interests are around preparation for adulthood and the transforming care agenda.

Julie cares for her son with special educational needs/disabilities.

### **Below from left to right:**

*Gail Walshe, Lara Roberts, Kay Moore, Dave Nutting, Maureen Morris, Mrunal Sisodia, Kath Bromfield, Nadhim Zahawi MP, Tina Emery, Julie Bruce, Zara Bowden, Fiona Beard*

# Engage



### **Kath Bromfield North West**

Kath joined the steering group in 2017 but has been part of her own forum for over a decade, currently as chair. Kath is a person centred planner, an expert by experience, and a trainer across many parts of the SEND arena and working with self-advocates. Her depth of understanding of inclusion and co production has been an asset to the steering group. Kath is passionate about ensuring we challenge each other to ensure everyone is enabled to be the best they can be. She has four children, is an active member of her local community, and is governor at a local secondary school. Kath has worked in education, as a teacher, in the past.

### **Kay Moore London**

Kay was elected as one of the two London regional steering group members in 2013. Kay is a member of the NNPCF Management team leading policy and consultation work, coordinating our national responses to policy and other key consultation opportunities.

Kay holds a degree in Health and Social Care and is also Children, Young People and Parent SEND Lead in her home authority of Bromley.

Kay is married with two sons. She has been instrumental in supporting her youngest son Luke to move into supported living in Bromley and is passionate about children and young people with SEND the same opportunities as their peers.

### **Lara Roberts South East**

Lara was elected to the regional role in 2015. She has extensive knowledge of the Children and Families Act 2014, delivering lectures to Trainee Social Workers at her local University as well as being extremely active within her region.

Lara also oversees our participation work, primarily supporting our team of National Representatives and ensuring all work streams we engage in meet the NNPCFs objectives and priorities.

### **Maureen Morris North East & Cumbria**

Maureen is the parent of a son and a daughter. Her daughter has Autism, a severe LD, Hereditary Spastic Paraplegia and the sure and certain knowledge that she is a princess who is loved and cared for by everyone. Her daughter has recently moved into supported employment and is also undertaking some supported part time employment.

Maureen having initially trained as a teacher she worked for many years a civil servant for the DWP and then left work to care for her family while her husband Ken worked away. She resumed work as a lecturer at an FE college until she was once again required to give up paid employment. She is a founding member and current chair of Sunderland Parent Carer Forum. In 2013 she was selected to become the Regional Steering Group member for the North East and Cumbria. In 2015 she was honoured to become one of the Co-chairs of the NNPCF.

### **Mrunal Sisodia Eastern England**

Mrunal is the father of two children. His son, Arun, was born very prematurely and has cerebral palsy, autism, epilepsy and learning difficulties as well as an insatiable lust for life.

Mrunal is the East of England steering group member for the National Network of Parent Carer Forums and since July 2017 has the pleasure of serving as co-chair. Between 2013 and 2016, Mrunal was the chair of Bedford Borough Parent Carer Forum and chaired the Eastern Region of Parent Carer forums in 2014 and 2015.

Prior to joining the NNPCF Steering Group, Mrunal was a director at Leonard Cheshire Disability and has extensive experience of the charity sector – developing strategy, business plans and new services. In a previous life, Mrunal was a director of strategic change management at Deutsche Bank and has over 20 years of experience of leading large, complex organisational change.

Mrunal is a passionate advocate of participation and co-production and believes that everyone has the right to be heard. In world of lobbying, campaigning and spin it is essential that the people who make policy, set budgets and deliver services hear the real, authentic voice of families living with SEND.

### **Tina Emery South West**

Hi. I'm Tina Emery and I'm one of the directors from Somerset Parent Carer Forum. I have two children, 18 & 16, one of which is autistic, severely dyslexic and suffers from hyper-sensory disorder. He attends a mainstream secondary school and is about to embark on his GCSE's. I have been part of the forum for over 4 and half years, but prior to that I have worked in education and residential social care. I love what parent carer forums are all about. I enjoy representing parent carers at all levels.

We have worked hard in Somerset to promote parent carers and I am extremely proud to be part of that team, as we represent them at all strategic levels within Somerset and I am now representing Parent Carers at a regional and national level and having been a regional representative for over a year.

### **Zara Bowden West Midlands**

Zara supports our communications and media channels. She provides support in managing our social media platforms and websites, alongside developing our annual conference and annual report in coproduction with our partners.

She is currently co-chair of her local forum and has been an active representative for them since 2012. She has a daughter with Cerebral Palsy and Hydrocephalus in mainstream education.



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

## National Network of Parent Carer Forums (NNPCF)

[www.nnpcf.org.uk](http://www.nnpcf.org.uk)

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For advice and information please call the  
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