

# Engage

# Enable

Annual Report  
National Network of  
Parent Carer Forums

# Empower



National Network of Parent Carer Forums  
'Our Strength is our Shared Experience'  
[www.nnpcf.org.uk](http://www.nnpcf.org.uk)

April 2022 - March 2023

Report compiled by Twenty Six Design

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# Introduction

## Welcome to the 2022-2023 Annual Report from the National Network of Parent Carer Forums

Every year we seem to start our annual report with 'What a year!' and this year is no exception.

We have started this year with a team like no other. We are now getting into the groove of what it's like being a community interest company and we are grateful to our members, our steering group, and our management team, for getting us to the point we are now.

The Annual Report is a look back of where we have come and an inkling of where we are going. COVID recovery is still happening and is still a topic on everyone's lips, as many of our families are still disproportionately impacted by the effects.

The SEND Green paper is now the SENDAP implementation, a joining up of SEND and Alternative Provision because it recognised that 80% of children that were in AP had special educational needs. The school's bill was scrapped and whilst the social care review report was released, we are still waiting to find out what and how these feed into the SEND AP work, and what it will look like for our families and future families. The SEND landscape is still harsh and difficult to navigate. The number of EHCPs is now at just over half a million, and these numbers are rising. The pressure on specialist school places and the pace of change generates more frustration in the system.

The new Ofsted and CQC joint Local Area SEND inspections were released with a greater focus on the 'lived experience' of the area. We still continuing to work with Ofsted and CQC to establish a consistent Parent Carer approach to the inspections, and we value all the feedback we receive from those areas that have been inspected. We never cease to be amazed by how much forums do while also carrying out caring for their own children, with such dignity and pride in trying to make sure co-production is at the forefront, to shape services for other families. 2022-23 will be the year remembered for its political turmoil with 3 Prime Ministers seen in Number 10 and with it came the reshuffles.

We have had 3 Ministers for children and families this year, with Claire Coutinho lasting the longest, but we have had no minister lasting more than a year, since Minister Vicky Ford in 2020-2021, with Edward Timpson serving 5 years in 2012-2017, making us question how important children and families to the government were, and how high on the priority list were SEND issues.

We of course continue to work with whomever sits in office, but we knew and felt the frustrations felt by so many, as we welcomed another Minister in the 2023 reshuffle. We know that the work will be hard over the next few years, with the newly announced Change Programme Partnerships, a real opportunity to learn where the 2014 SEND reforms failed. It isn't easy, there will be some difficult conversations to be had, along with the opportunity for positive change. We know how important it is to keep striving forward, and the need for good quality co-production, so that SEND services are fit for purpose for all families.

And finally, we want to acknowledge Mrunal Sisodia OBE and thank him for the work that he carried out whilst in his role as primarily the East of England regional representative, later becoming the co-chair and director. We are in a much better place as an organisation, because of your vision, which will live on within the organisation.



Tina Emery,  
Co Chair



Sarah Clarke,  
Co Chair

# Here are some of the partners we worked with this year:



## A snapshot of the year

51

Website news posts about our work

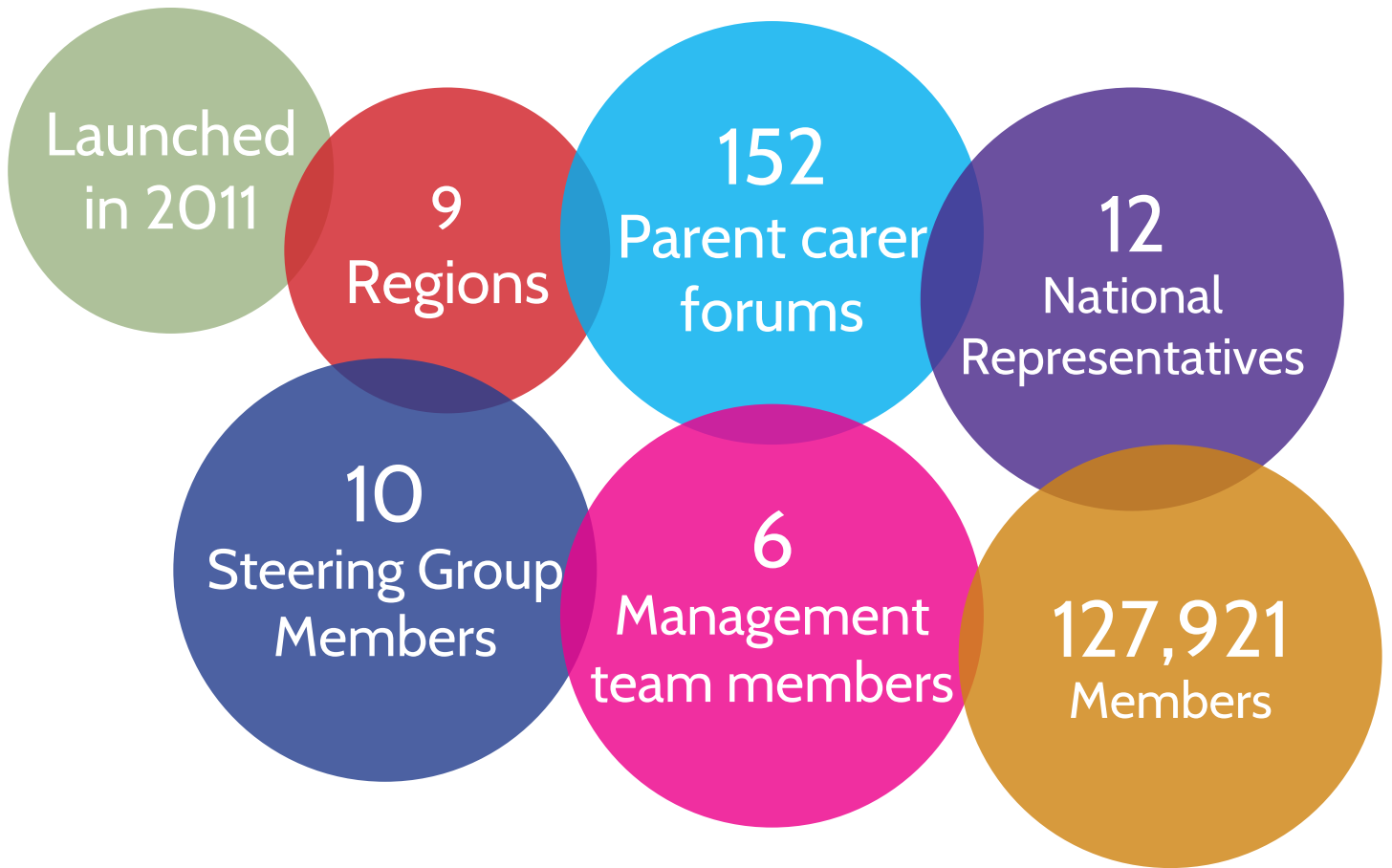
Over 1,200

Responses to SEND Green Paper review

1655

Days of work

## About the NNPCF



## Our work



# Introduction to the NNPCF

## Our vision and mission

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 152 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

# Meet the Steering Group

You can find full profiles of our steering group members on the NNPCF website  
<https://nnpcf.org.uk/blog/about/meet-the-team/steering-group/?amp>



**Tina Emery**  
*South West and Co-chair*  
southwest@nnpcf.org.uk



**Mrunal Sisodia**  
*East of England and Co-chair*  
eastofengland@nnpcf.org.uk



**Elaine Lambe**  
*West Midlands*  
westmidlands@nnpcf.org.uk



**Ros Luff**  
*London*  
london@nnpcf.org.uk



**Jayne Fitzgerald**  
*Yorkshire and Humber*  
yorksandhumber@nnpcf.org.uk



**Kath Bromfield**  
*North West*  
northwest@nnpcf.org.uk



**Richard Jaramba**  
*East Midlands*  
eastmidlands@nnpcf.org.uk



**Claire Richmond**  
*London*  
london@nnpcf.org.uk



**Jilly Russell**  
*North East*  
northeast@nnpcf.org.uk

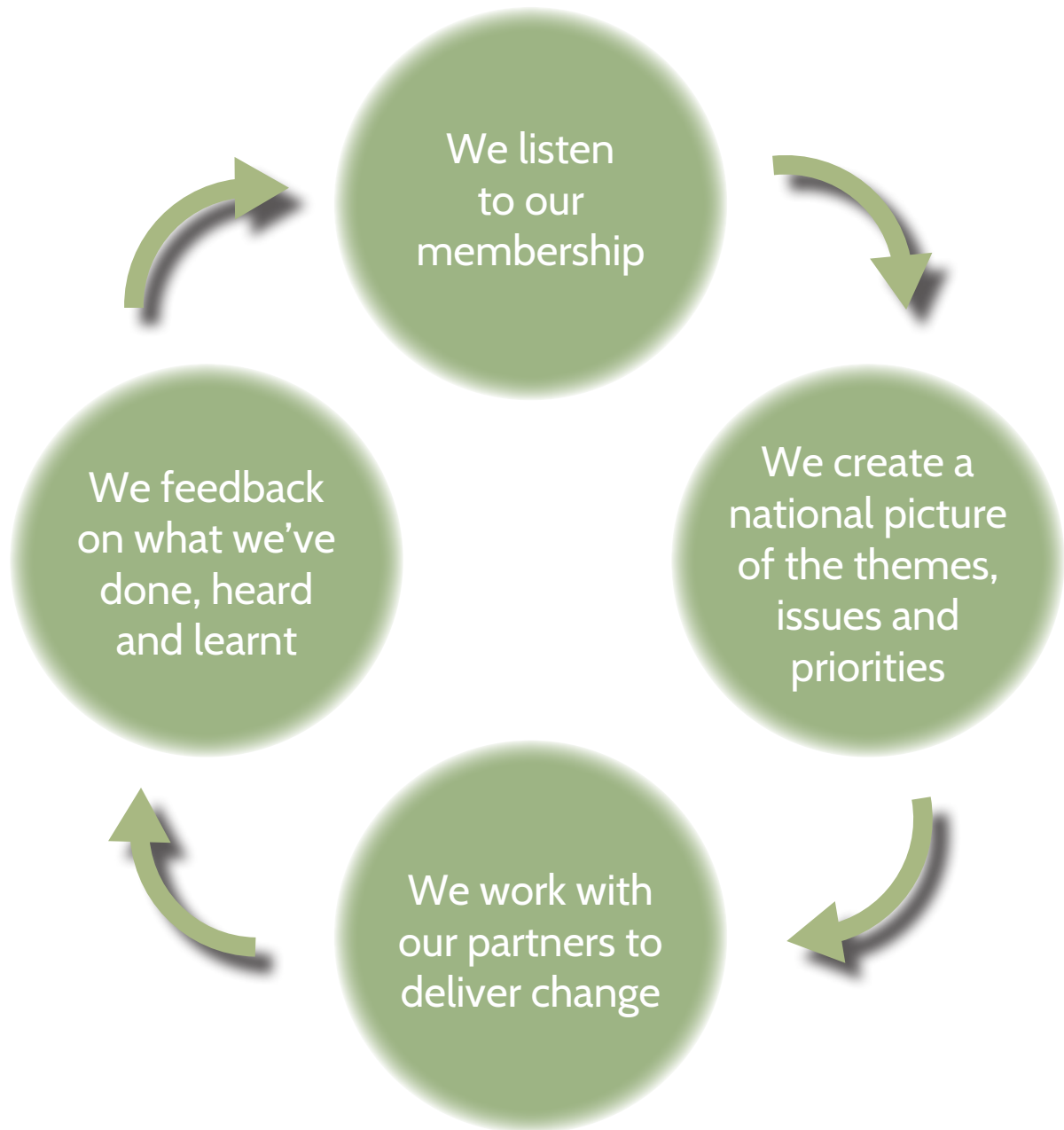


**Sarah Clarke**  
*South East*  
southeast@nnpcf.org.uk



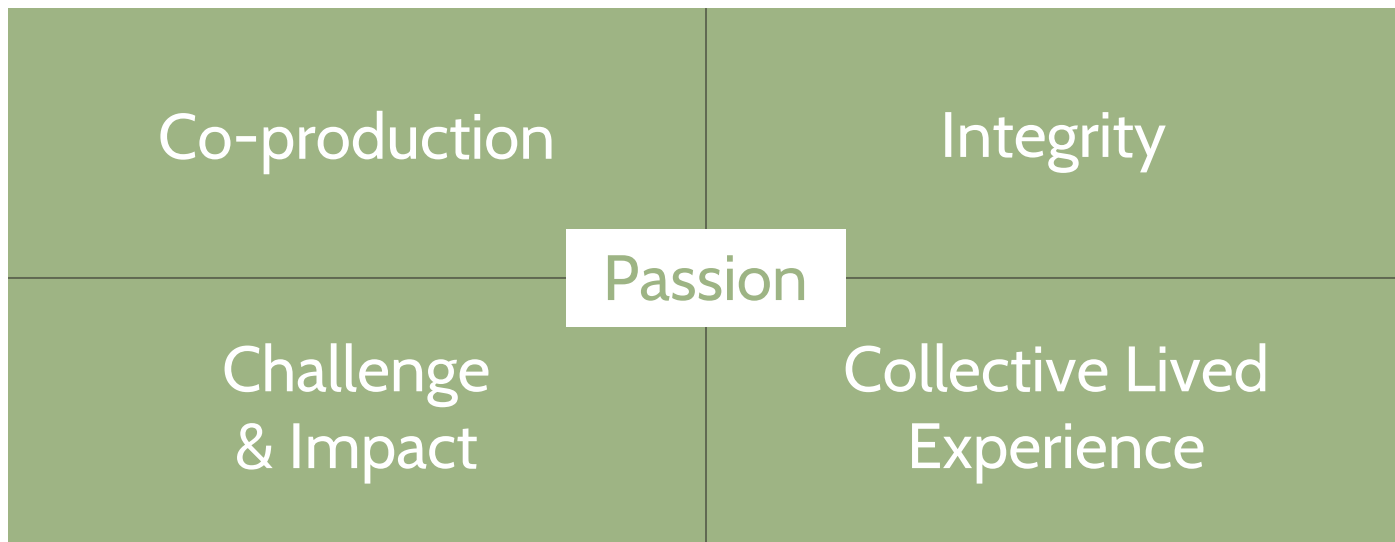
# What we do

We think about our work in four simple stages:



# Our Values

In early 2022 we co-produced a new set of values with our membership and stakeholders.



## Our Priorities

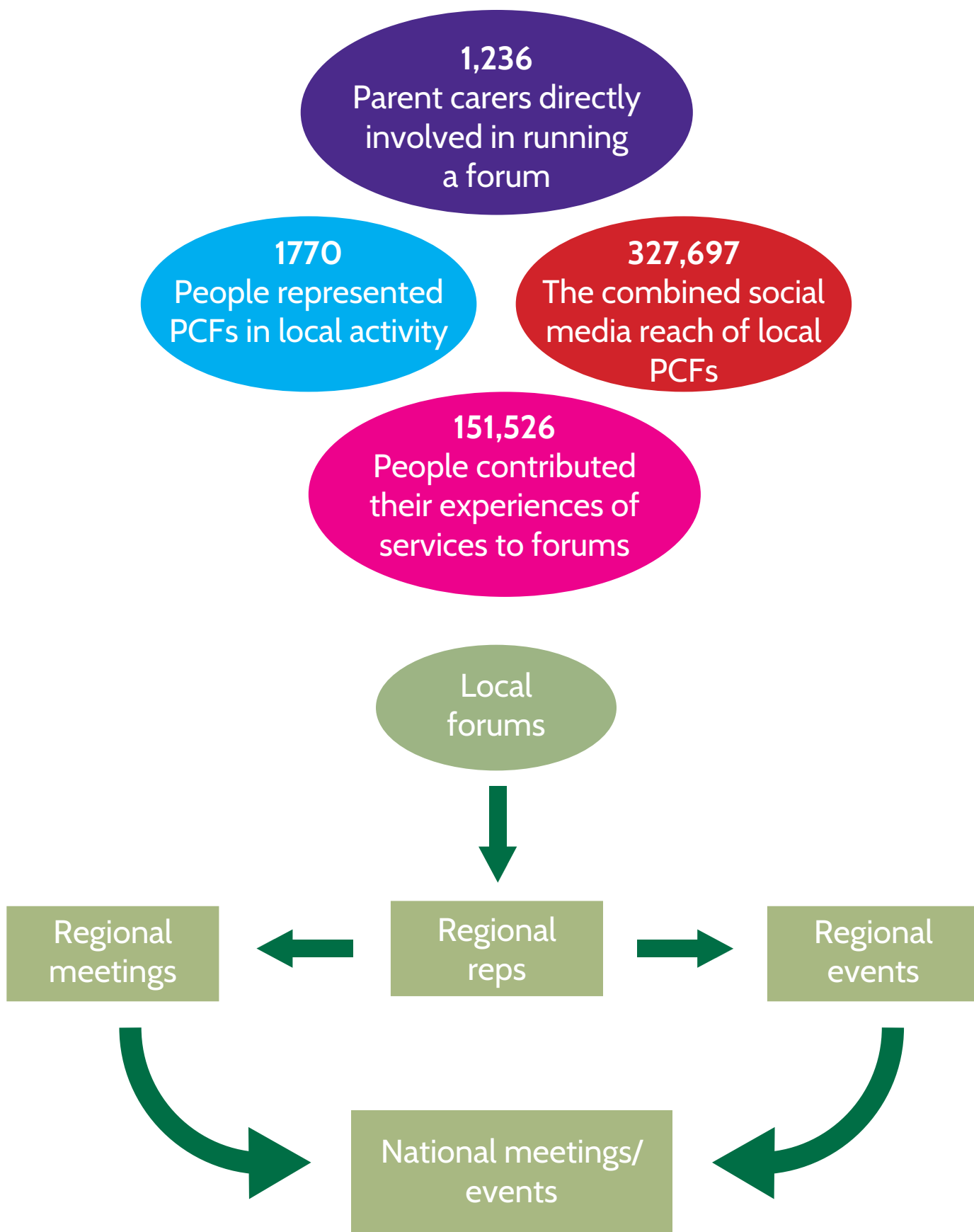
### Co-producing our priorities for 2023-2024

We also asked our membership to confirm and rank some of the key themes we have heard over the course of the year. They gave us the following priorities:

- 1<sup>st</sup> Wellbeing of parent carers (e.g. cost of living, health, etc).
- 2<sup>nd</sup> SEND green paper development and implementation
- 3<sup>rd</sup> Ongoing work to improve the system here and now
- 4<sup>th</sup> Partnership working with Integrated Care System (ICS)
- 5<sup>th</sup> Improving health services after the pandemic
- 6<sup>th</sup> New Ofsted and CQC local area inspection framework

# 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.



# Participation and our National Representatives

## Jacqui Watt - Participation lead

2022-2023 saw quite a change in the National Representatives team. We said a fond farewell to some very long term members, who had either a change in circumstances or retired. I want to thank them most sincerely for all the work they have done for the NNPCF over the years. This has meant we have been busy recruiting lots of wonderful new people to the team, who all bring a wealth of experience and variety of knowledge to the team. We held a fantastic face to face National Reps day in Birmingham, where a large number of us came together to get to know everyone and discuss challenges and solutions to them. A number of the team also came to help out and facilitate table discussions at the Contact and NNPCF Conference in Bristol at the end of February.



The team has been involved in some really useful and interesting pieces of work throughout the year, including the creation of a Conflict Hub with NHSE, attending the British Association for Supported Employment Conference, Resetting Services to Disabled Children following the pandemic, lots of work with University students and researchers including Relationships and Sex Education, and the SEND Awards to name but a few!

We also arranged multiple focus groups around the SEND and AP Green Paper which was attended by lots of parent carers outside of the NNPCF team, and I would like to thank them all for giving up their valuable time to participate and share their experiences.

The National Rep team contributed to over 600 hours of work this year, which is a huge increase from the 214 hours from the year before, and clearly demonstrates how much work is currently happening within the SEND world.

I would like to take this opportunity to thank each and everyone within the National Rep team for all their hard work and insightful contributions they made and continue to make.

Find out more on our website: <https://bit.ly/NNPCFnationalreps>

## Join our national representative team

To become a national rep, you need to be a strategic member of your local parent carer forum. This could be in any position, such as chair, treasurer, or parent carer representative, paid or voluntary. You do need to have the support of your forum when applying to be a part of our national representatives' team. This is because of the nature of the role; you may need to travel and have portions of time where you are not available to your local forum. Although we support you to balance this, your forum needs to be aware of the commitment this role may require of you. You will also need the support of your Regional Steering Group Member. We are currently seeking representatives from the South East, North West, London, West Midlands and East Midlands regions, but welcome applications from any parent carer forum representative.

Please email Jacqui for more information [participation@nnpcf.org.uk](mailto:participation@nnpcf.org.uk)

# Consultation and Policy

## Claire Fisher- Consultation lead

Consultation April 22 March 23

This year we said a fond fair well to Kay Moore and welcomed Claire Fisher to the NNPCF team. It has been a busy year in the consultation space. The SEND and AP improvement plan green paper was the first time NNPCF had sought views directly from parent carers as well as PCFs. We received over 1200 responses, which helped inform the NNPCF response to the green paper consultation.

Following on from this, the NNPCF have started collecting case studies on various topics from parent carers directly to try and further inform the national picture. We are looking forward to analysing these over the coming year. Despite the dominance of the SEND and AP improvement plan consultation in the early part of the year, the NNPCF has continued to respond to various consultations and parliamentary inquiries. The establishment of Integrated Care Boards and how they are interacting with PCFs has been another area of focus. As well as reaching out to forums to gather evidence for the national picture, the NNPCF has been working closely with the Health Policy Influencing group (HPIG) to analyse how well ICBs are fulfilling their duties towards children and young people in their improvement plans. The NNPCF has increasingly engaged with parliamentary select committee inquiries on various topics that affect CYP with SEND and/or parent carers. Talking points have been reviewed, and feedback sought from PCFs and National reps on how to develop them further. This work will continue into 23/24. There is now a live consultation briefing which is updated most weeks, as well as a downloadable version available.



### Our wider policy work

The NNPCF are members of the Special Education Consortium (SEC) and Health Policy Influencing Group (HPIG).

The Special Educational Consortium (SEC) is a group of organisations who protect and promote the rights of disabled children and children with special educational needs. SEC work with the Department for Education, members of parliament, and other decision-makers when there are proposals for changes in policy, legislation, regulations and guidance that may affect disabled children and young people and those with SEN.

HPIG is a group of children's health charities who work with the Department for Health and Social Care and NHS England to discuss proposals for changes in policy, legislation, regulations, and guidance that will affect children and young people, including those with SEND.

### Policy Briefings

Our Policy Briefings continue to keep parent carer forums informed of national policy developments. You can find our policy briefings here [Policy Briefings – National Network of Parent Carer Forums C.I.C](#) ([nnpcf.org.uk](http://nnpcf.org.uk))

## Finance and operations Claire Powers - Finance and Operations lead

We had our first full year of operating as a Community Interest Company (CIC) having completed the transfer from being a constituted group under Contact's umbrella in October 2021. All of our Steering Group and Management are now employees as of April 2022 and we continue to streamline our processes as we become more established in our own right. No major systems changes took place in 2022-23 as we sought to embed those we had put in for the start of CIC operations.



## Communications Melissa Chesman - Communications lead

This year, we have continued to grow our communication channels. We have regular participation and consultation updates that are shared on our website and social media channels.

This coming year we will be looking at applying for a grant for our new website. This will be a project that will see all the work the NNPCF does come together and presented on a new platform to ensure our PCF's are kept up to date with the work we are involved in and opportunities for our members to participate in to help improve the lives of our SEND families. We will also be looking into designing a new logo and branding.



# Our work this year

It has been a year of reflection. The SEND Green paper review released its survey and anybody and everybody in the world of SEND gave their feedback on it.

We had been saying for years that whilst the 2014 reforms were good and what our families needed, the structure supporting those reforms weren't clear enough and lacked accountability.

There was an increase in punitive approaches for those with SEND within the systems (progress 8, Need for diagnosis to get support and help) generating additional barriers for many in being able to access education, costing the government and parents dearly. EHCP numbers are rising and have hit half a million and tribunals currently have a waiting list of over 12 months.

The NNPCF SEND Review Survey, had over 1200 responses, the most we have had as an organisation. The information from this survey provided us with a wealth of information which has been fed into all our work, not just the SEND review work. Nationally, the government's survey received over 30,000 responses, many of which, like ours, were from organisations with large membership.

We have had lots of changes within the government this year; 3 prime ministers, 3 secretary of states and several children and families ministers all in a matter of weeks. This could have delayed the SEND review work, but it didn't. The SEND AP Implementation Board was formed as recognition that 80% of children and young people in alternative provision have Special Educational Needs and Disabilities.

The School's White Paper on the academisation of all schools became a bill and then it was scrapped, elements though are feeding into the SEND review work.

Attendance in school had become a buzz word. Attendance figures were still not at the level they were before the pandemic and special schools, in particular, were struggling getting children into school following the pandemic. A new board was formed, the Action Attendance Alliance, governed by the then secretary of state for Education Nadhim Zahwari, and the NNPCF were invited to be part of it. Attendance conversations were sometimes tough, pushing our point across that for some children, it's not that they won't attend, they can't for a variety of reason. The children's commissioner also released an audit report, that stated all children should be in school and called for 100% attendance, and forums, along with NNPCF raised serious concerns about how 100% attendance was just not possible for many of those with SEND.

In light of this, we started case studies, the first being around those families who have children who struggle with school and the findings were shocking. We had families whose children were on 30 minutes a day of education, with some part time timetables being in place for more than 6 years. We heard from families whose children had were self-harming, because they couldn't go to school, due to fears and massive anxiety issues. We also heard from families whose children had no school to attend.

The NNPCF shared these stories anonymously and we are really grateful to those families who shared their stories. The conversation with the Action Attendance Alliance Board are ongoing why some children can't attend school, and we continue push this narrative.

Timeliness of Education Health and Care plan reviews was reviewed, and we are still waiting to hear the final outcome of the government's consultation. We fed into this consultation and many more like it, we shared it on our channels as we felt it was an important issue.

In Health there were changes within the organisations. Health Education England (HEE) blended into NHS England, with some job losses, but there was plenty of work to do.

Vaccinations, in particular for those ethnic minority families was a piece of work we supported. Fazilla, our London representative led on this piece of work, to increase awareness of the importance of vaccinations, including those for COVID.

We were lucky enough to be given the opportunity to bid on £5,000 in our regions for admission avoidance. Admission Avoidance project was aimed at supporting families that had a child and young person with Autism and or learning disability who were at risk of inpatient mental health intervention. NHS England felt that being an inpatient, often far away from home, should be the last straw. They wanted to inform families that there are options before their young person should have a hospital stay. There have been some legacies in this project, including a video developed in the South East and digital booklets developed in the South West region, both still being used today.

NNPCF led the keyworking community practice work. Where forums were coproducing keyworking in their local areas, an important programme for children and young people who have mental health needs as well as autism and or learning disability. The early adopters led the way, but year 2 and 3 were about to get started. The programme is popular and has done some really amazing work. Funding now goes to the ICB's, so pressure will be on parent carer forums to make sure that this work continues to happen.

The Care, Education & Treatment Review (C(ET)R) and Dynamic Support Register (DSR) policy was published and many forums across the land have been making sure that the quality of these important reviews are increasing. There is still confusion of who is held on a DSR and how long there are on the register and forums will supporting this work, so that it helps families.

And as if all this work isn't enough, they stop Delivering Better Outcomes Together (DBOT) and the government looks at improving local areas as well as sufficiency.

Ofsted and the Care Quality Commission started the new framework local area inspections, focusing on the outcomes of children and young people. There are still some inconsistencies, and we are gathering feedback from forums who have had local areas inspected, so that the new inspections can be consistent.

Safety Valve (SV) was started in 2020 and due to the low level of comms around this project, many forums are concerned that a lot of the agreement has been done with little coproduction with PCF's and local partners. In 2022 Delivering Better Value for SEND (DBVs) was launched, with 3 tranches. Focusing on what data and people's lived experience is telling local authorities and where there are gaps.

Safety Valve was open up to 20 local authorities with the highest deficit and DBVs was open to 55 local authorities with the next highest deficit.

The RISE consortium was formed to replace DBOT. Looking at area improvements, so more than a training course. Monitoring of Local Area's still took place before and after and those monitoring sessions helped shape conversations around what interventions are needed to improve local areas.

The NNPCF will continue gathering feedback from forums, who have gathered theirs from parent carers. We will still have conversations at regional levels, weaving in what local areas are telling us and we will still have conversations with those who lead on work that affects those families who have children with additional needs, because all change starts with a conversation.



# Regional Annual Reports

## East Midlands

The East Midlands Regional Network has seen changes in its leadership team. We are grateful to have Robert Martin the Chair of Leicestershire SEND hub taking up the chairperson's role after Georgina Nottinghamshire and Jo from Nottingham had served their terms. We thank our outgoing leadership and wish them well in their next endeavours.

The new leadership under Robert is working with Contact, community matters to update policies and reengage all forums. The regional team is looking for a co-chair to work with. Individual forums have seen changes in their leadership, but the regional grouping is steady and supportive of all the changes in forums. Derby City has a new-look forum, and the new look forums in Northampton will complement the ten forums of the East Midlands region.

### **New Inspection Protocols**

The new inspections protocol is now in use, evaluating all SEND provisions and commissioning in Local authorities. Nottinghamshire and Rutland have been inspected in our region. The inspection result for Rutland has yet to be out, but the consequences for Nottinghamshire have caused the region to reflect and pay attention. The experience satisfaction of parents and young people in these inspections is very different. Forums throughout the region will host a training seminar to determine what is required of them in inspections. Parents are showing great satisfaction with the new inspection, but what is expected of them is what is in question.

### **Health and Social Care**

The New Inspections track the provisions in a child's life, including inspecting the local area within a shared Integrated Care Board (ICB) footprint. The ways of commissioning across the joint ICB footprint have become a focus. The ICBs across the East Midlands now understand areas of weakness from inspected areas in their footprints. These inspected ICBs in the inspected regions are now expected to work with parents and children to improve the provisions, parent and children's voice, and joint commissioning across their footprints.

The big health concern in the East Midlands and Nationally has been the ever-growing waiting lists for CAMHS and Neurodiversity Diagnosis. The ND pathway developments within LLR are worrying, with some parents in areas resorting to private ND diagnosis, causing feather deprivation to families and complicating the EHCP provision processes in the region.

The keyworker project under the DSR and CETRs has brought confidence to coproduction to a new level between Health, Social care, Voluntary sectors, Forums and, in some cases, Experts by Experience.

## Education

The changes in the Department of Education from a regional view are now being recognised. Forums have much work addressing the strict ministerial demands on children's attendance in schools. Some forums are under so much pressure from campaign groups who want to tackle the issues of attendance head-on. The reforms have brought additional alignment issues in academies and council schools.

## Projects

The East Midlands is slightly behind in the Autism in Schools projects. The project has changed, which may see a more significant uptake in the region.

We would want to thank NNPCF and Contact our regional DfE, SDA, NHS and SEND leaders for their strength in keeping the forums informed and active in their coproduction duties with their local authorities. We emerge stronger together to share our joint strength in our commitment to improving the outcomes of children.



# West Midlands

This year has been a year of consolidating and emerging priorities for the region. As a region we have continued to attend the West Midlands SEND Forum bringing together representatives from the different Local Authority areas and all forums are now invited to these meetings.

Heather Delany represented the region at the Midlands SEND Leadership Programme and presented an introduction to parent carer forums to the aspiring leaders from across the region.

Forums have been busy with their individual work with highlights from our forums include:

- Birmingham Parent Carer Forum, Solihull Parent Carer Voice and Warwickshire Parent Carer Voice worked together with their local areas to coproduce a guide to school engagement as part of the Autism in Schools Project
- Sandwell Parent Voices United have improved coproduction with services and played a large part in the development of Sandwell Inclusion ECO system ready for their Area SEND inspection.
- PACC (Shropshire) launched their healthy lives demonstrated how creative use of funding and limited resources can deliver long term impact. Most importantly, it's changed and improved lives
- Solihull Parent Carer Voice held a SEND Community Event bringing together children, young people, parents and professionals from all areas to talk about what's working and what could be better-feedback from the event informing priorities across education, health and social care for the year
- PODS (Telford and Wrekin) produced a "Working Together Charter" and have gained funding for a perinatal / early years SEND worker highlighting the role of the new family hubs in supporting earliest diagnoses of disability and getting Preparation for Adulthood Navigator service based on parental feedback. They were the first area in the West Midlands to be inspected under the new SEND inspection framework
- Warwickshire worked with Genuine Partnerships and co-produced an Inclusive Schools Charter and Working Together Charter
- Worcestershire Families produced co-produced a Parent Carer Engagement toolkit, employing a member of staff to deliver this piece of work in schools

## Parent Carer Voice Herefordshire

We found that lack of easy information and support families were overwhelmed and not given the time to process the situation they found their families in. We at PCVH decided to develop a booklet with simple information and links to sites so that if parents wanted they could search for more in-depth information. This has proven a great resource and the local Portage workers have embraced it wholeheartedly with some lovely feedback from them and the parents coming into their service

<https://www.flipbookpdf.net/web/files/uploads/be4a665f9062741ff483eaa0f310079d2ee08b6fFBP27554020.pdf>

# East of England

The last year has not been easy for families of children with SEND or for parent carer forums. We are still facing the backwash from the pandemic with long waiting lists for community services, many schools failing to be inclusive and many children struggling with anxiety. As ever forums have risen to the challenge and relentlessly represented the lived experiences of families through work such as conducting surveys and gathering evidence, participating in recruitment and hosting successful conferences.

Forums themselves have been under pressure with the volume of work and some facing challenges from other parents. However, the community has drawn together and provided advice to one another through several peer support events throughout the year including ones on capacity building and campaign groups. In addition, the East of England peer network has modelled the value of four way coproduction with education, health, social care and families.

Across the region, work with our colleagues in health has dominated – we have participated in (and in some cases led) work on Neurodevelopment Disorder Network networks, key working, autism in schools and the Building the Right Support regional board. Continued good relations with key regional players including peer network leads, the regional schools director and SEND / LDA leads helped the region play its part in providing challenge, holding to account and driving change.

This is my final report as your representative on the NNPCF steering group. It has been a pleasure and a privilege to serve and work with such a great group of people. Many of you will have heard me say that our regional meeting is the most important in my calendar. What I maybe didn't say often enough, is that it has also been my favourite. I have been lucky to have such a well-informed, passionate and supportive region to work with. I will miss you all.

However, I know that I leave you in very capable hands who will take you onto new heights. Julia and Philomena are great national representatives (and I am confident that more of you will sign up soon), Sarah will be a calm and authoritative chair and Jo has been a tremendous support who will seamlessly replace me. And what would we be without Sylvia who is the heartbeat of the region? Many thanks to all of those who have worked alongside us over the years and a special thank you to Karen who stood down as regional chair earlier in the year.

My final words to you are on a more reflective note. This year we lost three much loved colleagues: Helen from Hertfordshire, Nicola from Norfolk and Julie from Contact. The wonder of parent carer forums is that we have incredible resilience – Helen, Nicola and Julie would want us to continue their work with the same passion, determination and compassion they did. I know that you won't let them down.

# London

This has been another challenging year for the London region.

There have been a number of boroughs where the forum work is going through a period of renewal. Most notable is Havering who are regrouping following the unexpected death of their long serving Chair, Karen Street. Richmond, Waltham Forest and Harrow also lost members of their team this year. All are sadly missed. We also have a number of forum leads/ reps who are struggling with serious illness and/or losses from their close family. One of our two London regional representatives, Fazilla Amide, stepped away to achieve a better work/life balance. Whilst Fazilla set a hard act to follow, Claire Richmond has stepped into the role and become a valued member of the team. Despite the challenges our forums have continued to represent parents, with some of the successes shown below.

Richmond ran a workshop to help parent carers understand and engage with the Local Area's Written Statement of Action. It was a complicated but impactful event well attended by both parents and practitioners. This resulted in several parent carers volunteering to work on strategic projects with the LA. We received positive feedback from all corners, including thanks from our members ".... for running a successful and informative morning."

Hammersmith & Fulham developed a Post 19 Co-production coordinator project. This was funded by Adult Social Care. The project focussed on Adult services, Health, Social care and Education and encouraged carers of adults to engage in co-producing those services. They also received funding from NHS to run Parent Carer Wellbeing sessions for parents in partnership with Chelsea FC Foundation and Hammersmith and Fulham Mind. The sessions alternated between physical activity and mental health workshops.

Westminster forum helped parents to engage with the Short Breaks Team, through this they were able to get the Direct Payment policy amended to be more flexible for families. Through their work around preparing for adulthood the forum were pleased to see their suggested tracking panel was set up to help develop smoother transitions across social care.

Kingston forum held a successful launch day and have developed strong parental feedback for the SEND review. Their area SEND Ofsted report made comment on the value and robustness of the feedback of the forum.

Merton forum were invited to speak at Merton's Annual SEND Conference open to all professionals involved in supporting children and young people with SEND in the borough, across Health, Education and Social Care. This proved a great opportunity to share the role of the forum. Their work in partnership with IASS on transition to secondary events proved successful with the IASS reporting a subsequent reduction in casework with families on this topic as a result. At the request of the local libraries, the forum canvassed membership for SEN book suggestions. The membership produced a comprehensive list of book recommendations.

Hillingdon forum maintained good working relationship with the local authority, and hosting many successful events, including an engagement day tea with the Mayor, whilst simultaneously refreshing the core team, policies etc.

## Regional Work

As a region we have come together at cluster meetings and information sessions, including an IPSEA legal update. We continue to develop the regional contacts with strategic leads including ALDCS Association of London Directors of Childrens Services, LIIA London Innovation and Improvement Alliance, LSMN London Strategic Managers Network and NHS London region.

We are developing a regional representative team for health to help forge coproduction within the five new Integrated Care Systems in London and are grateful for the funding from NHS for this work.

Some of our forums have been involved in delivering the Autism in Schools project for the region. Again, we are grateful for the support & funding from London NHS, along with the partnering with Autism Education Trust.

We ran a number of information meetings with Linda Jordan from NDTI National Development Team for Inclusion, to discuss the London Internship Programme and how forums should be involved in these.

The above is a small snapshot from just some of our forums and the regional team. We also welcome a few new and emerging forums and we look forward to hearing their successes in the future. Claire Richmond and Ros Luff would like to extend a huge thank you to all of our forums for their efforts. Croydon Active Voices Parent Carer Forum launch.



## North East & Cumbria

“The North East & Cumbria forums have grown into a force to be reckoned with over the last few years. Since I joined as NNPCF Regional Rep just before Christmas last year I have barely stopped, we are not afraid of a bit of hard work up here that’s for sure!

We have really worked hard to secure and improve our relationship with partner organisations, particularly the North East and North Cumbria ICB, which is the largest of the 42 integrated care boards. We are able to work closely with the bordering Yorkshire and Humber team and look forward to working together even more in the future.

Our forums have been incredibly busy organising their own very successful events in the first half of 2023, with North Tyneside having their conference in the last couple of weeks, Northumberland having had theirs recently and Durham’s just happening a matter of days ago and many other events going on and being planned. We’re a busy lot!

The Autism in Schools Project is still growing each year and we are incredibly proud of our forums for working so hard. Every year we add schools to our project and with each school comes new learning opportunities, new experiences and new challenges.

Our regional team are working with NNPCF to help support the forums and create a supportive environment, with our more established forums helping our newer forums and sharing our strengths and we are looking forward to hosting a regional conference in the new school year to celebrate the last few years of hard work and spend time together in person.

We could not do any of this without the support of the lovely Sarah Lee from Contact as well as the rest of the team that she works with and obviously to every single individual forum member, thank you for working hard to improve the system. It is not un-noticed and we appreciate each and every single person within forums.”



## North West

This year presented many challenges and opportunities for the North West as we moved away from the immediate effects of Covid to start to see the more medium term impact on society, professionals, our membership and the forums that support them. Below a few highlights.

With planning around the new ICB's gaining momentum the North West met as clusters to start to think about the strategic partnerships that happen at Cheshire & Mersey, Greater Manchester, and Lancashire footprints. This started with GM who throughout the year established regular meetings and have received some funding to continue this at ICB level. All areas met and started to think about how this would look for them.

We continued to work with our NW Children's Board partners to lead around strategic co-production within areas that have not traditionally engaged. This meant working with Youth Focus NW around children and young people's voice and starting to build relationships with public health.

The North West PCF's were successful in a bid to lead on a sensory project in partnership with Alder Hey Children's Hospital, Edge Hill University, NdTi and Contact. This project was driven by the region and involved a number of forums particularly Liverpool and Sefton. You can access the project below using the link provided and some of the learning has already helped children and young people across the North West access the hospital appointments and their stay in hospital.

Following the success of this project we embarked on a bid to the National Institute of Health Research (NIHR) for funding to look at health inequalities and access to health care from our under-served communities. Whilst the work for this with PCF's will happen in the following year we were successful due to the strategic PCF and co-production within the bid. This has the potential to be helpful to PCF's nationally around our under-served communities but also to impact and influence the way academics approach working with lived experience at a strategic level.

As always the forums in the NW work tirelessly locally and regionally to support families, their forums, other PCF's and NNPCF and Contact. The way we collaborate and support each other is something else and I am so proud of our achievements this year.



Scan the QR code to find out more about the Alder Hey Children's Hospital Project





## South East

We all continue to feel the prolonged pressures and fallout of the pandemic across all areas of forum work including the impact on our member families and for many of us personally too. The resilience and the drive of forums, to remain solution focused, to improve the daily lives of our families never ceases to amaze and inspire me, and this year has been no different.

At the end of this financial year, Andrew Howard, Chair of FACT Bucks, stepped down as our Regional Chair. Andrew's dedication to the work of forums and the region has been enormous, something we are all truly grateful for. Personally, I thank Andrew from the bottom of my heart, as he has been a wonderful mentor, from my 'newbie' days as a forum chair, through to becoming a Regional Rep for the NNPCF, his support and advice has always been invaluable. Thankfully, Andrew isn't stepping away completely, his good humour and support will still be there from the sidelines.

As a Region we have reviewed and developed our regional structure and now have a Regional Steering Group, made up of 5 forum representatives. We appointed a new Regional Chair, Lisa Scarrott, Medway PCF, who I am excited about working more closely with. We have also welcomed a new administrator to the region, Caroline Hambleton, who offers much needed admin support.

We have worked hard at maintaining and rebuilding relationships across the regional footprint with partnership organisation, which with staff changes, and restructuring hasn't always been the easiest of tasks. We have received amazing support from our Regional SEND DfE Advisors, Liz Flaherty and Mark McCurrie, in championing the importance of forums role to our LA's and providing forums with regular updates at our Regional meetings.

Thank you too to our Contact advisors, Sue Mennear, Sarah Lee and Julie Singleton. Julie's passing was a huge shock to the region and her enthusiasm for participation will be missed. Julie had worked with forums and promoting engagement for 9 years, and was very much an integral part of the region, who was always happy to offer help and support wherever she could.

And finally, thank you to all the South East PCFs, for all the information sharing and feedback when you are all so incredibly busy, for the humour, support, solutions and the shared 'eye rolling'. You are all amazing.



## South West

Looking back at previous annual reports fills me with pride. One of the smallest regions in NNPCF, with 15 forums, we are held in such regard, that I am so pleased we are here.

When I started this regional rep journey in 2017, we had no real region to speak of. We had been held together by Sue Mennear at Contact, for which I am, and I know others are eternally grateful.

We had our 2023 national conference on SW soil, and it was the first time that the national conference has done so, and we came together in true partnership. We show others what partnership working looks like and our partners were there with us. We are the only region to work so closely with our DfE and NHSE partners together.

Funding for co-production work continues to be given by NHSE SW. We continue to work on looking at gaps within a child and young person's journey, a project that I am hopeful will steer how our partners work with families, to then secure more funding which will look at a more unified regional hospital passport.

Our admission avoidance booklets continue to thrive, with views from just under 3000 views in the last annual report, to over 12,000 and the views continue to grow, a double-edged sword that these booklets are needed.

Our Autism in Schools programme, which is now in year 2 and covers half of the south-west, with nearly 100 schools having autism training. Parents on the pathway also are receiving strategies and training, so far 400 families have received this, with numbers growing as the programme continues, something again we are being recognised for nationally.

I always say in my report how we work together as a team, and we truly do. No one person can achieve what we have achieved here in the SW. We are a group of parent carers who have the same ethos, values, and drive to change the experience of our families for the better and we are fortunate to have partners who believe in the same things.

My tenure comes to an end in October 2024 and it is always a worry when you take something on like this, but I have been truly blessed. Thank you as always to you the forums, Our NHSE SW and DfE teams, to Ruth & Kay who have supported the region, to the national reps Kay, Claire, Kenton, Ruth & Richard and of course Sue and Kate from Contact – I couldn't do it without you all.



# Yorkshire & Humber

Yorkshire & Humber Regional Network of Parent Carer Forums work in partnership with statutory bodies to improve the lives of children/young people with SEND aged 0 to 25, and their families. A representative from each of the Y&H DfE funded PCF's, alongside the NNPCF regional steering group rep and the regional Contact adviser, meet monthly in different areas of the region. It meets to;

- Ensure we have collective, equitable voice across the region, supporting each other via peer-to-peer support.
- Share living/current experience of SEND families to inform local, regional and national priorities.
- Strengthen independent parent carer voice and lived experience.
- Promote and embed co-production in each local area across all areas of SEND.

Our restructure has enabled us to work together more easily, with Co-chairs and regional admin bringing us together monthly, and individual PCF voice being collected on a range of SEND priorities.

Our next step is looking at how we can share resources to support each other in supporting the families we serve.

Our forums range widely in Y&H, some new and some very established, all amazingly passionate and working tirelessly, each one bringing their gift to the regional forum that strengthens the voice of families across the region.

This past year, via consultation and building on our regional restructure, we identified a priority around engagement with health and local authority at a local level. The feedback was very mixed from forum to forum and so in partnership with regional colleagues from NHS England, we are holding a conference in Leeds (North East and Yorkshire NHS region) for 29 local areas to come together with their PCF to work together on the Learning Disability and/or Autism priorities presented by families, ICB place and Local Authority.

Forum and family priorities arising from voice remains our priority and steers everything we do.

Moving Forward we recognise that each of our forums is very unique and operates differently, sharing our good practice and learning from each other as one community strengthens the voice of all families across the region. Formalising this in a focus on gathering voice will strengthen our voice with partners and give opportunity for more partnership working that is coming from the living experience of our families.

Our consultation results across the region gives us a clear understanding of the priorities of families, this experience is what is presented and included at regional and national meetings, particularly important as the SENDAP plans are implemented.

We are proud of the countless and innovative ways that individual forums in Y&H are making a difference for families, despite frustrations, hurdles and the heartache that we continue to hear from families at local level. We are especially proud of our co-chairs and admin worker who have guided us through the restructure and drives the steer that brings us together monthly, ensuring that lived experience is at more tables across our region and is included in developing services for our families with SEND, all over and above the work they do for their own forums.

Thank you to every child, young person, parent carer, forum who have contributed this year, together we really can make a difference.

# Notable Forum Work

Parent carer forums across England do amazing work and we are grateful to every single one of them. Here is a taste of what some of the forums do.

## Swindon

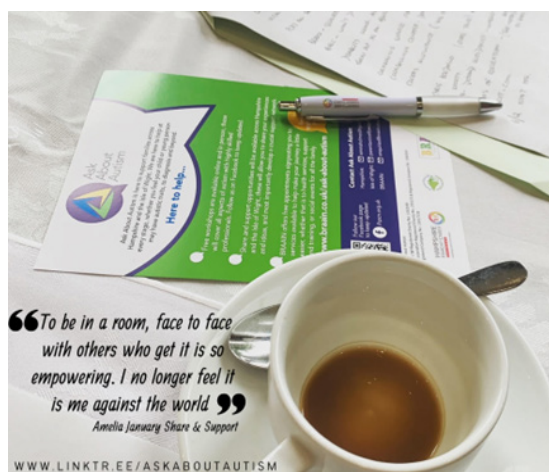
Pride of Swindon award and coffee mornings in schools.

We have been visiting as many schools as we can to tell them about Swindon SEND Families Voice and to give information about the services we run. We also use this time to reassure parents/carers and offer support. We are able to signpost parent carers to other service in Swindon. We also use this time to speak with school staff, so they can signpost parents/carers to us, and share our leaflets to the SEND community in school. Our coffee morning has been very successful, and we are usually asked to come back and do follow up visits. Because of this work and other work that we do, we were awarded a Pride of Swindon Award, which was a wonderful way to celebrate everything we do for the SEND families in our area.



## Hampshire

Ask About Autism supported 337 parent carers across 9 months hosting 41 sessions across Hampshire with Share & Support - an opportunity for parent carers to share their personal stories in a relaxed and neutral space and to be given further advice, guidance, and ideas to help them support their young person. The aim of these peer support sessions enabled parent carers to feel less isolated and to find a network of compassionate individuals who truly understand. In addition to Share & Support we managed to host 1451 Hampshire Parent Carers in 29 workshops with neuro-affirming professionals helping to develop the toolboxes for families to better support their young person, some of the great topics we managed to cover included Autistic Burnout, Developing Positive Self-Esteem, Sleep, Motor Skills, Sensory Processing just to name a few. The workshops were run online and in-person during the day and evenings to ensure we reached as many Hampshire Parent Carers as we could. Future in Mind will continue the great work Ask About Autism started by working with neuro affirming professionals to help develop positive mental health as well as onsite with CAMHS professionals talking about key mental health topics.



## Haringey – Voices Day

On 7th March 2023 SEND Power in Haringey jointly hosted a Voices Day with the Local Authority (LA). Young people, parents and professionals came together to talk about SEND in Haringey – where we are now, what's working well, and what needs to be developed.

It was facilitated by the wonderful Genuine Partnerships team. They've developed a tangible working model of co-production based on four cornerstones:

- Welcome and Care
- Value and Include
- Communication
- Work in Partnership

We invited young people, parents/carers, Haringey SENDIASS, as well as Health (leadership, Speech and Language team, CAMHS), Education (leadership teams and SENDCos from both mainstream and special schools) and the LA (SEND leadership, Educational Psychologist team, Statutory Assessment team, Language and Autism Support Team (LAST), Housing, and Commissioning) to come to this event. It was well attended.

Parents/carers and the young people had an opportunity to speak about their experiences in a safe, non-judgmental environment and the professionals listened. It was heartfelt, raw, and particularly moving.

There was a great buzz and willingness to work together, in genuine collaboration. We still have a way to go but as with anything it begins with a positive step. This Voices Day event was the first of many tangible positive steps in facilitating real & positive change in all aspects of life for our SEND children & young people.

Following the Voices Day, Genuine Partnerships provided us with a report, summarising the day and everyone's views, and pulling together some priorities and recommendations.

We are using this report to help inform the action plan for our communication and co-production working group.

This table did well during the activity! Genuine Partnerships gave us materials and asked us to work together to build a structure that could hold an orange for 10 seconds. While we all enjoyed it, they reminded us that for something to be genuine co-production, all partners need to pool their resources together, decide together what to build, and work together to build it.



## Herefordshire – Early Years Information Booklet

We found that the lack of easy information and support, families were overwhelmed and not given the time to process the situation they found their families in. We at PCVH decided to develop a booklet with simple information and links to sites so that if parents wanted to, they could search for more in-depth information. This has proven a great resource and the local Portage workers have embraced it wholeheartedly with some lovely feedback from them and the parents coming into their service. To read the booklet, click here <https://tinyurl.com/538a7jaw>

## Essex – Neurodiversity information packs

Essex Family Forum develops a neurodevelopmental resource for families: ‘Supporting Your Neurodiverse Child’. Essex Family Forum worked with local support groups and two local charities – Send the Right message and MyOTAS - to develop and co-write a book as an information resource for families living with neurodivergent Children and Young People (CYP) across Essex. The production of the resource included the input of Parent Carers, CYP, as well as professionals across Education, Health and Social Care and is available both online and as a hard copy.

### Identifying the Need:

Essex Family Forum identified this resource was needed Essex-wide: There was very little information given to families up to, and at, the point of diagnosis. There was a heavy reliance upon less structured resources, such as self-learned research, networking with other families, and support groups. This led families to feel very isolated at key points in their CYP’s neurodivergent diagnosis journey. Other conditions, e.g., diabetes, had far more comprehensive and consolidated support and information available at that time.

### Essex Family Forum’s Actions:

- Successfully drafting and presenting the proposal for this resource to the Joint Commissioning Board (JCB).
- Gaining JCB agreement for the availability of printed copies for all parent carers in Essex, including for the two neighbouring Essex Authorities; Thurrock and Southend.
- Ongoing management of the funding, printing, and distribution process for this entire project.
- Actively involved in reviewing and updating the resource at regular periods for both the online and printed version.
- Securing three years future funding for over 10,000 printed resources for families in Essex.
- Managing and facilitating the option for professionals to obtain hard copies at cost price for print and postage.
- Promoting the resource, which has been distributed to every Essex school, libraries and Family Hubs as well as included on Health ND Pathway letters.
- Managing enquiries and implementing a joint agreement with the two co-writing charities to allow for a generic version of the resource to be distributed in other Local Areas

### The Impact:

- Decreased isolation felt by families up to and after the time of diagnosis.
- Improved access to information
- Increased confidence, empowerment, and ability to engage with SEND professionals.
- Greater autonomy and self-reliance of families to ensure that their CYP get the best possible support.
- Improved understanding, continuity, and productivity between Health, Education and Social Care professionals through joint working.
- Confidence for families and professionals that the resource is proactively reviewed for accuracy and relevance, with changes implemented for future print runs.
- Significant interest in a generic version of the resource that has the locality-specific information

removed - Nine Local Authorities have already taken up this offer.

#### Family Feedback:

- “I have been a SEND parent for 12 years, have hundreds of books on neurodiversity and have never seen anything of the depth and quality of this resource”.
- “This is answering questions that I didn’t even know I needed to ask”.
- “You are going to make the journey that you went through so much easier for other parents”.
- “I want everyone I know to read this so they can understand my son better.”
- “Wow, this is what I have been looking for”.

From a ND adult /parent carer: “Can’t help but think how different my life would have been if people had the knowledge and understanding that you are getting out there.”

For more information about Essex Family Forum and the Resource go to [Neurodiversity - Essex Family Forum](#)



### **Bexley – Lived experience sessions**

#### Bexley Voice – Lived Experiences 2022/23

As part of our work with the LA, Bexley Voice facilitated four Lived Experience sessions during 2022/23. The sessions were an opportunity for Parents and Carers to share their experiences and contribute to discussions with key professionals who work to support SEND families in Bexley; including the Head of SEND, Head of the Early Intervention Team, Designated Clinical Officer and the Local Offer Lead. This enabled them to gain a clearer picture of families’ lived experiences with SEND children – enabling them to build on good practice and improve the journey for families in the future. Each session had a different theme as follows:

Session 1: Noticing there were differences in my child’s development.

Session 2: Seeking Advice and Support Related to my Child’s Additional Needs.

Session 3: Securing an Educational Setting for my Child.

Session 4: Specialist support and advice over the years.

The sessions were well attended with session 3 having the highest attendance of 13 parents.

Key themes and issues were identified during each session with actions noted and taken back to the relative teams.

Parents and Carers fed back that they found it a positive experience and felt listened to.

Full details of the themes identified, and the outcomes can be found on [Lived Experience Outcomes - BEXLEY VOICE](#)

## Rotherham

We facilitate inclusive family activities and 2 youth clubs (all come for YP voice and preference)

Listening to families from early days in 2009, what they wanted and still want is social activities as well as focus groups, drop in etc. RPCF gather voice and living experience where our families are, and this gives a real opportunity to hear young person voice and the impact of local services on the whole family. Services, elected members, often visit to speak to families directly.

Families pay for the activities, and we work with local businesses, cinema, community groups etc, to adapt bespoke sessions for cyp with disabilities and their siblings. It's a win /win as we often negotiate a reduced rate and businesses have a full house at times that would be very quiet for them. Our amazing volunteers keep these activities going alongside our activity's coordinator Kay, who facilitates and keeps everyone safe.

Obviously, the biggest win is the look on the faces of our children and young people, and the reduced isolation of parents, equally is the voice and experience of Rotherham services we are able to gather. As we have weekly and monthly activities, the voice is always current.

If you are a parent carer forum and you would like to feature in next year's annual report, please contact us.





# What will the next 12 months bring?

Every time we close our annual report, we use it as an opportunity for reflection and this one is no different.

We are still reeling from the effects, even after being out of lockdown for quite some time and whilst we are not using the words COVID recovery, COVID is still part of the conversations with services that we are having.

The effects of the post pandemic are seen every day. Services struggling even more with waiting lists and backlogs, schools struggling to recruit and retain staff, and the effects the pandemic has had on everyone's mental health is clear to see. Pre pandemic attendance levels in schools has not returned to what it was, creating a board to specifically deal with the situation.

Whilst it sounds positively grim, and at times as an organisation we have had to hold our breath over the last few years, there is hope. There is a glimmer of light that is shining through the darkness, and it is emerging, with forums leading its charge.

The SEND AP work is a positive. We are not sure where this will end up, where it will finish and what it will look like, but parent carers and their families are at the centre of this new bold move. The change programme partnership is the new buzz word, but it's more than that. It's a golden opportunity, a once in a lifetime event as Tina stated at its launch, to try things out, to see if it works, not with one local authority, but with regions.

The conversations, the consultations the events that you have taken part in over the last year, with many more happening in the future, have got us to this point. Our narrative, from your conversations have helped shape this new future and you should be extremely proud.

We will endeavour to keep those conversations going, because we need to make sure that our membership is at the centre of this brand new world.

Mrunal Sosodia

Tina Emery





National Network of Parent Carer Forums  
'Our Strength is our Shared Experience'  
[www.nnpf.org.uk](http://www.nnpf.org.uk)

Contact us

**NNPCF**

Email: [info@nnpf.org.uk](mailto:info@nnpf.org.uk)

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

NNPCF  
124-128 City Road,  
London  
EC1V 2NX

Find us on  
Facebook and Twitter  
[@NNPCF](https://www.facebook.com/NNPCF)

**TWENTY SIX**  
DESIGN

Report compiled in December 2023  
by Twenty Six Design