

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

April 2021 - March 2022

Report compiled by Melissa Chesman,
Communication lead for NNPCF

Introduction

Welcome to the 2021-2022 Annual Report from the National Network of Parent Carer Forums CIC.

For the past two years, we have started the introduction and report with “What a year!” and whilst that still seems fitting, as we are all still dusting ourselves off from the COVID pandemic, we actually want to start with “look at what we did.”

This NNPCF annual report, will be the first of many as a fully fledged community interest company. With it comes new roles and responsibilities, which you will see in our meet the team on page five

Not only have we as a group of parents had to negotiate the care of our young people in the aftermath of a global pandemic, but we have also had to absorb, not only for ourselves but for the families that we work with some very big strategic pieces of work.

Whilst in the last report, we were waiting for the SEND Green Paper review report, it was like waiting for buses, because not only did it arrive, carrying with it the review of Alternative Provision, but the school White Paper arrived the day before, then the following week the review into children’s social care and the Health Bill.

The SEND landscape at this present time still looks grim. The number of EHCPs is rising, as is the need for dispute resolution, but our forums are still at the coal face, doing what they do best: co-production, even in the face of some extremely harsh conditions.

You have exceeded all expectations in your capabilities of stepping up when times get hard, and you continue to try and improve the services for all SEND families because you know that this is the best chance for all children and young people with SEND to exceed in their outcomes.

We have high aspirations for all our young people with SEND and this is what drives us, and we are extremely proud to be part of this movement.

Please read our first annual report as a community interest company, you have done some amazing work, which always inspires us to do more.

We are in this together, and it promises to be an extremely busy few years!



These are some of the partners we worked with this year:



A snapshot of the year

40

Website news posts about our work

1400

Different discussions on our closed group

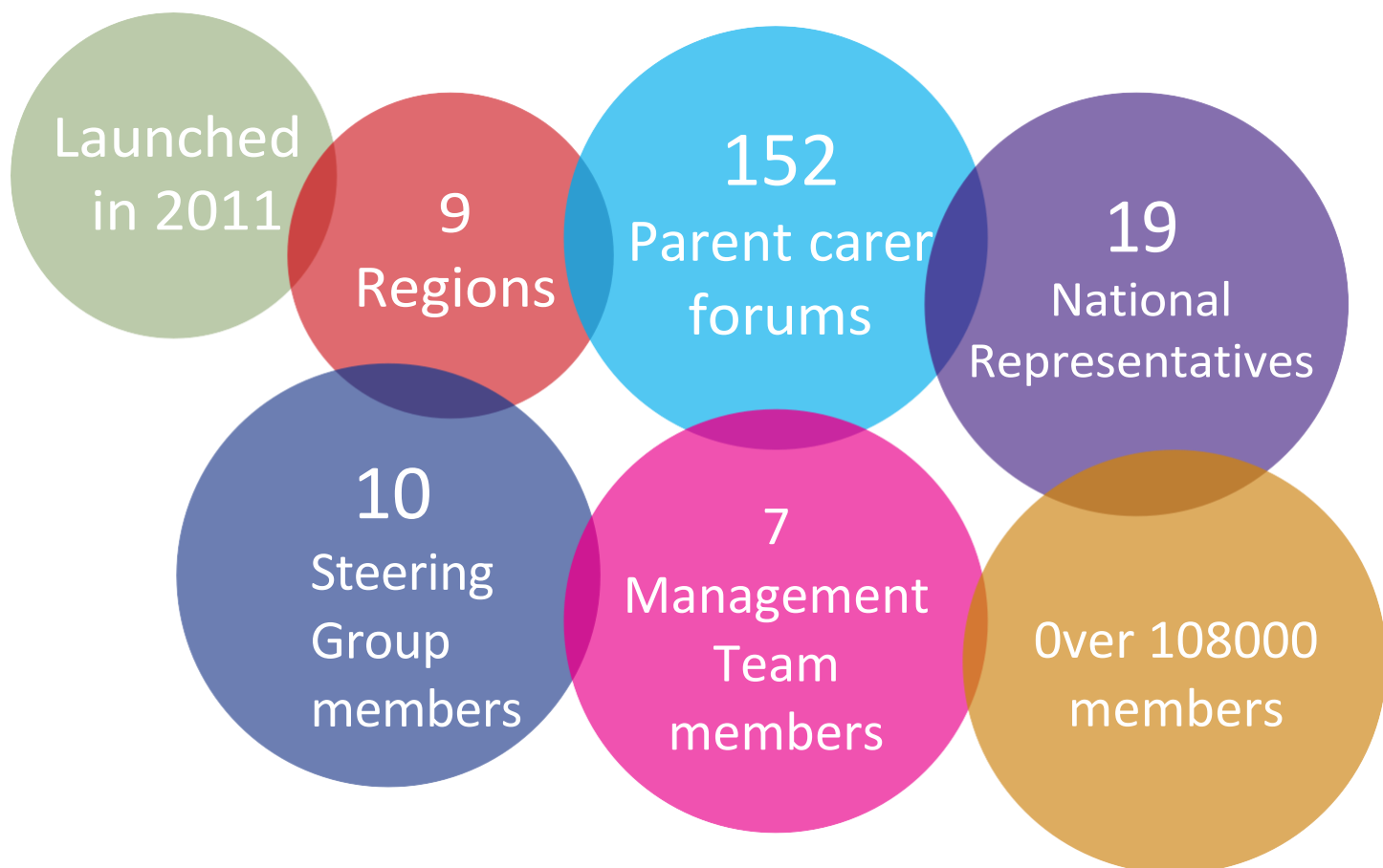
26,626

Hits on our website

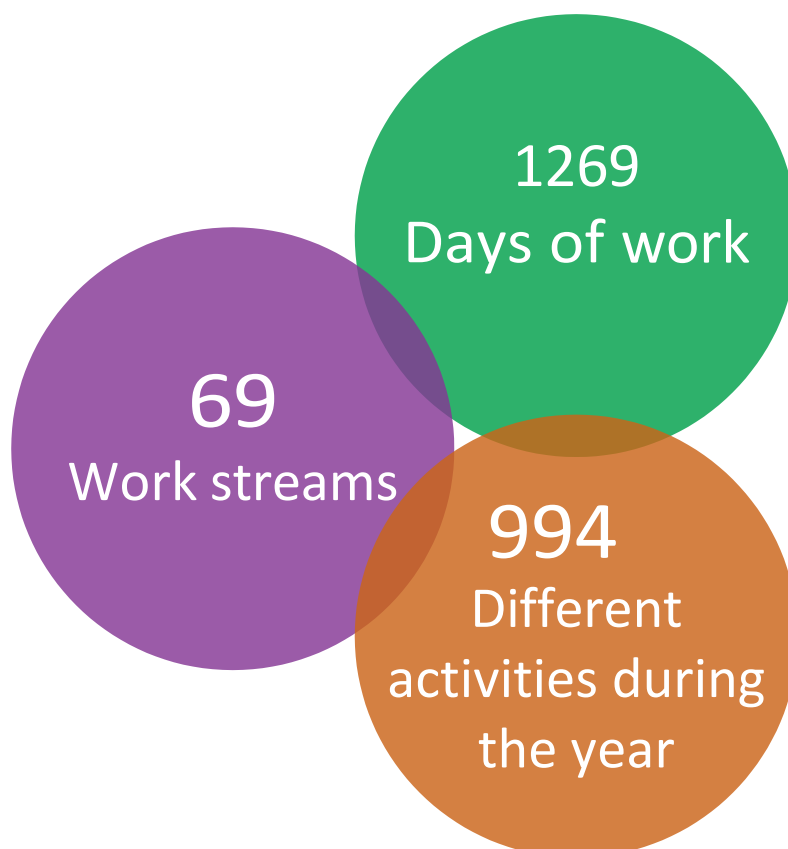
671,000

Facebook reach

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 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 own 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 the 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://bit.ly/NNPCFSGMEMBERS>



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
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Ros Luff
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Jo Gilliland
North East
northeast @nnpcf.org.uk



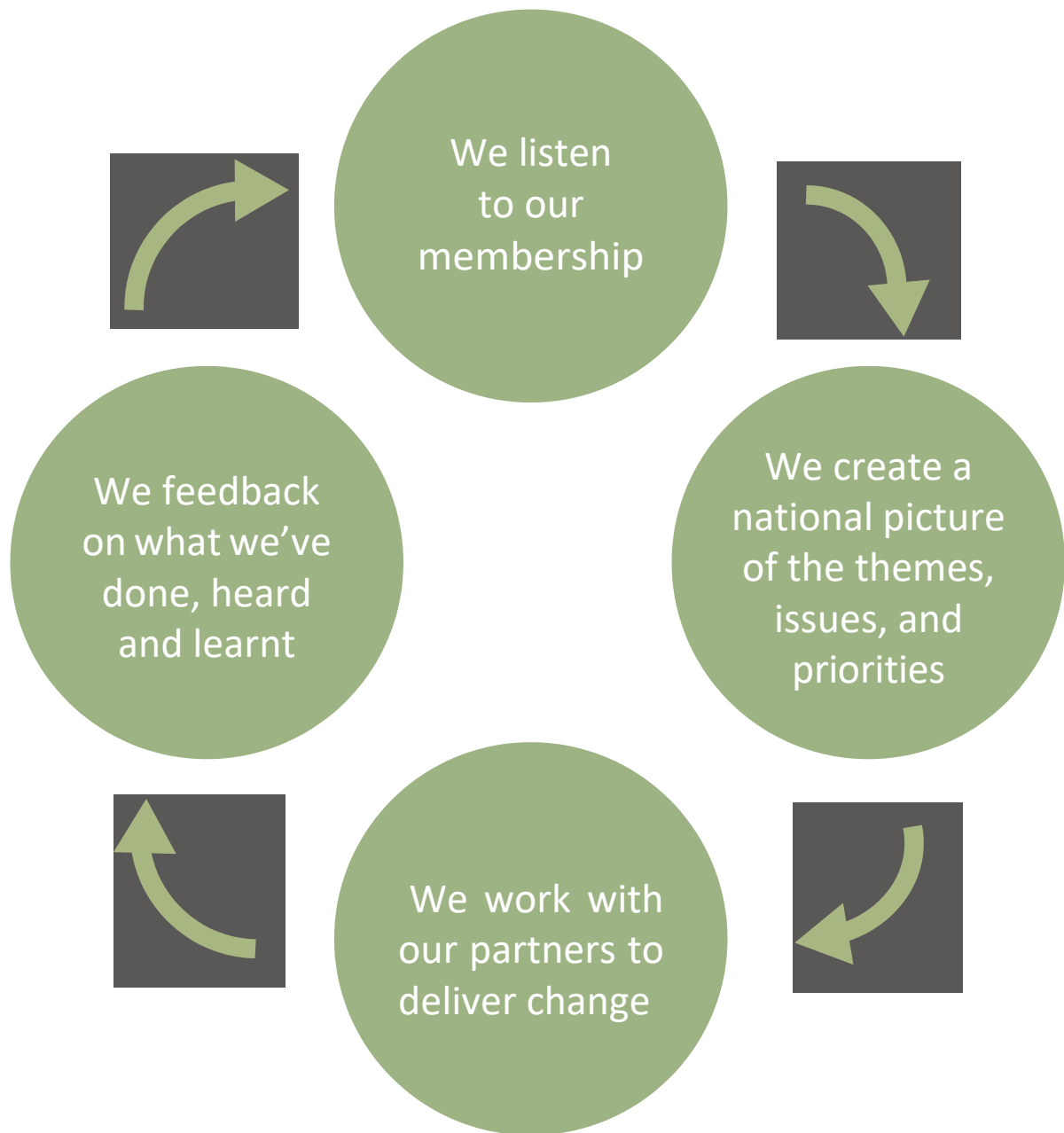
Sarah Clarke
South East
southeast @nnpcf.org.uk

This year saw a number of changes to the steering group. Richard Jaramba joined as the representative for the East Midlands. Zara Bowden stepped down from her West Midlands role and Elaine Lambe stepped up to replace her. There was also a change in Yorkshire and Humber as Julie Bruce resigned and Jayne Fitzgerald joined the team.

We would like to thank Zara and Julie for their dedication and hard work not only to the NNPCF, but everything they have done to empower parent carers forums too.

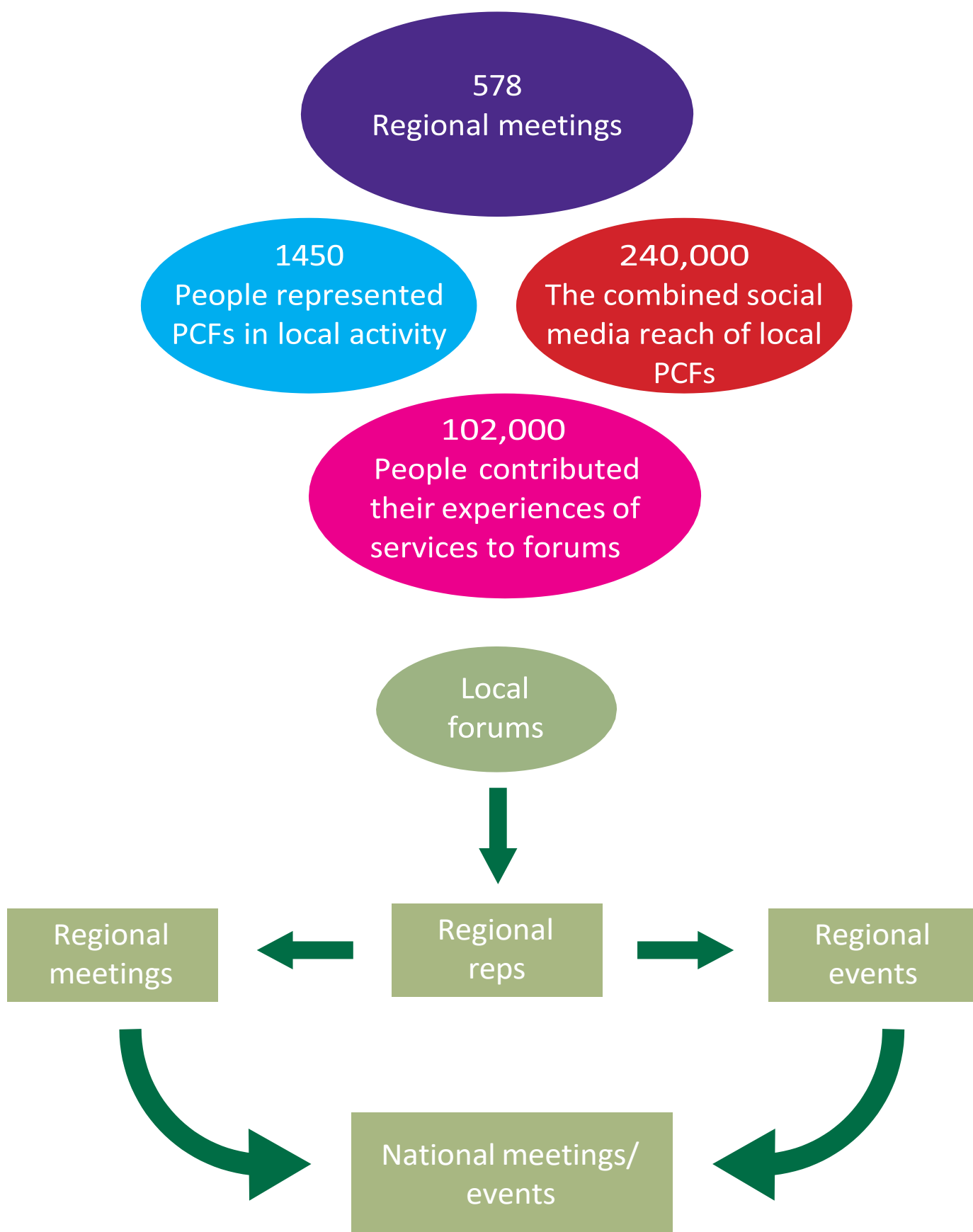
What we do

We think about our work in four simple stages:



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.



Our work this year

A year of two halves

The 2021-22 year had two very distinct themes. The first part of the year was dominated by Covid 19 – the impact, the response, the recovery, and the start of the restoration of services. The second part of the year was about the big strategic initiatives that will shape the future of children and young people with SEND for the next 10 years – the SEND Green Paper, the Schools White Paper, the review into Children's Social Care, and the NHSE Long Term Plan.

Covid 19

The first and most important thing to understand about Covid, is that the pandemic and its wake are far from over for families of children and young people with SEND.

Exacerbating existing harms

During the pandemic, many key services were interrupted or disrupted. Many children and young people no longer got the support they needed because they could not access schools and respite providers and many health services were diverted to deal with the crisis. All of this meant that conditions worsened for many children with SEND and they emerged from the pandemic in a significantly worse situation than when they entered it.

Creating new harms

In addition, the social isolation and fear of the virus experienced by many children caused new harms to be introduced with mental health concerns and anxiety increased significantly over the period. New concerns were not recognised, and many children missed out on early identification and help that could have made a big difference to their lives.

The long road back to normal

Services face huge challenges to catch up on the backlogs and in trying to meet the demands of the emerging harms from the pandemic. SEND families are reporting long waits for services, most notably paediatricians, SALT and CAMHS, and increasing more problems with emotionally based issues in attending school.

But parent carer forums did a remarkable job through this period

PCFs provided everything from virtual coffee mornings to peer support; from signposting services to working strategically across systems to mitigate the impact of covid; from conducting surveys to championing the parent voice at a time of crisis.

And this allowed the NNPCF to make a difference nationally.

Relying on the evidence that local forums provided, we were able to make a big difference through our national work.

For example:

- We highlighted the issues faced by children returning to school after the disruption of lockdown which has led to additional support measures being introduced by the Secretary of State.
- We added text on the importance of coproduction and reasonable adjustments to the Omicron guidance issued by the Department for Education.
- Made changes to the guidance on school catch up monies to make clear that they should be spent on holistic catch up, not just academic, and worked closely with NHSE to improve the uptake of the covid 19 vaccination for children with SEND.

Building the future

As the country emerged from the pandemic and resources were freed up, many vital initiatives for children and young people with SEND restarted and for the latter part of the year, much of our focus turned to making sure these deliver for the SEND community.

The SEND review, the Schools White Paper, and the Children's Social Care review.

NNPCF co-chairs, Tina Emery and Mrunal Sisodia were invited to join the rebooted SEND review steering group. After some consideration, we agreed to join the group with the understanding that this would give families a voice in shaping the review and it would not be just a rubber stamping exercise.

We made many representations on behalf of our membership and were successful in getting some of the key provisions we were looking for included in the SEND Green Paper published in late March – most notably the requirement for national standards for SEND services to be established. Equally well, there were several unwelcome elements most notably the requirement for EHCP placements to be chosen from an approved list of schools.

If anything, the school's White Paper is even more important than the SEND Green Paper. This will frame the environment in which all schools operate and so will shape the priorities, incentives, and accountability of the system that children with SEND are schooled in. We have major concerns about the headline emphasis on attendance and behaviour but beyond this, there are some necessary measures in the proposals about the regulation of academies and the importance of inclusion.

PCFs also engaged extensively with Josh MacAlister and the children's social care review – most notably through an interactive webinar in which we were able to feedback to the team in the early stages of the review. These proposals, taken together, will form a new settlement for children and young people with SEND in the schools and social care system. It's too early to say whether these initiatives together will make the changes that children with SEND desperately need. There are encouraging and worrying signs in all the proposals and the key will be how what the landscape looks like once the connections, gaps, and disconnects between the three are clearer.

The NHS Long Term Plan

The Long Term plan picked up real momentum in 2021-22. In particular, the Learning Disability and Autism workstream started rolling out some of its flagship projects. Most NNPCF regions were heavily involved in the admissions avoidance work which highlighted the importance of Dynamic Support Registers and Care Education and Treatment Plans.

In addition, the Keyworking and Autism in Schools projects continued their rollouts across the country, again with heavy involvement from NNPCF regions and local parent carer forums.

The work of the NNPCF was recognised as we were awarded a 3-year contract to be the strategic partner for the Learning Disability and/or Autism project along with our partners at Contact.

And finally, setting up as a Community Interest Company

The NNPCF established a community interest company (CIC) in December 2019. However, the onset of the pandemic prevented us from transferring our operations to this new legal entity for almost 2 years. In particular, we found it very difficult to set up a bank account as many banks shut up shop for new businesses.

We are very grateful to our partners in Contact for continuing to support us through this period.

However, on the 1st of October 2021, we cut across to running the NNPCF out of the new CIC.

So far, the process has gone very smoothly and despite a few small bumps there have been no significant problems. There are enormous benefits for the NNPCF such as being able to access funding in our own right, making sure that NNPCF staff have access to key employment rights such as holiday, sick pay, and pensions and enshrining the role of local parent carer forums in setting the strategy and direction of the NNPCF.

We continue to work very closely with our partners at Contact and we will maintain that link between the local forums and the national body.

Participation

Jacqui Watt- Participation lead.

2021-2022 was about re-invigorating the National Representatives team.

The pandemic brought about so much change for us all that we needed to refresh and regroup as a team.

I became Participation Lead in November 2021, so I have spent my first 6 months in post getting to know who our National Representatives are and onboarding new members to the team. We currently have 19 team members, and we have been becoming more actively participating with national stakeholders again, as more workstreams have opened back up following the pandemic.

The National Representative Team attended over 300 hours of participation work throughout the year.

We have developed eight new teams, which include both Steering Group members and National Representatives, to increase joint working and provide a more cohesive feedback process.

The teams span core areas such as Education, Health, and Accountability.

I would like to thank the National Representatives for their patience while I settled into my role and look forward to an exciting and busy year for our team!

Meet our reps

"I have met, worked with, and continue to learn from some great people who are passionate about children and young people and representing the views of parents and carers, relentless in their efforts to make positive change and I am privileged to be able to call many of them colleagues across the parent carer network. I am always learning something new and deepening my understanding of the "system." Not only does this benefit me in my representation of parent carer views for the NNPCF, but also within my own local forum and other forums within my region."

Jo Harrison, national rep since 2020



"The main appeal for me in becoming a National Rep was being able to influence national developments that could help to make positive change locally for the benefit of our children and young people.

You have the chance to work with a wide range of professionals, often leaders in their disciplines or areas, whilst keeping the child and family front and centre. I also enjoy picking up new ideas, knowledge, and contacts"

Carol Kelsey, national Rep since 2014

You can find more about our national reps on our website: <https://bit.ly/NNPCFNATIONALREPS>

Our Values

At the beginning of 2022, we set out to create a new set of working principles and values to guide the day-to-day decision making at the NNPCF and identify a set of behaviours to work and live by in all that we do.

With the help of Simon Hawtrey Woore, we asked our partner organisations and parent forums to identify keywords that they associated with the NNPCF and to describe what the words meant to them.

Our Steering Group met with Simon to focus on the results and agreed on a set of aims and principles to adopt. These were then shared with our membership at the second part of our conference.

The words and phrases we decided on were:



Thank you to everyone who has been involved in this process.

The words and the sentiment behind them are being used to design our new logo and branding which will be launched in the new year.

Our priorities for 2022-23

Listening to our membership, we agreed on four priorities for the 2022-23 year. We believe these are the big items that will make the biggest difference in the outcomes for our children

Support the recovery from Covid 19

Ensure that the parent-carer voice is heard and work with the government and the NHS on the covid 19 response and recovery to ensure that children with SEND are not further disadvantaged.

Understand and articulate the impact on key SEND areas such as EHCPs, annual reviews, community services and short breaks.

The SEND Review & wider policy initiatives

Engage in the work of the SEND review to support the DfE to create the far-reaching changes we believe are necessary.

Engage with wider policy initiatives including the DfE school's white paper and the Social Care Review

The NHS Long-Term Plan & other structural changes

Represent SEND families in the development and implementation of the NHS Long Term Plan which delivers many important changes that will support our children including Learning Disability and/or Autism, the SEND workstream, and mental health. Also empower the SEND and parent-carer voice in the implementation of integrated care systems and other structural changes in health care systems

Improve accountability in the SEND system

Work with Ofsted and the Care Quality Commission to develop the next phase of local area inspections.

Our Policy and Consultation Work

NNPCF Annual Report 2021-22 – Our Policy and Consultation Work

Kay Moore Consultation and Policy lead

During the past year, our response to the SEND Review has been a key focus of our policy and consultation work including several national and regional engagement events with representatives from DfE. In July 2022, the NNPCF responded to the SEND Review Green Paper. Our response was based upon over 1200 responses to a national survey which was shared with parent carer forums and the wider SEND parent carer community.

Beyond the SEND Review, we continue to prioritise our policy work in line with our own strategic vision and priorities.

Our Approach to our consultation and policy work as a membership organisation, is based on a range of sources including:

- Feedback from forums through their regional networks to their Steering Group member.
- Feedback on our social media platforms.
- Feedback at engagement events with representatives from DfE, DHSC, DWP, and NHSE.
- Key issues identified through direct conversations with parent carers at a local, regional, and national level.
- A national survey of parent carer forums on the SEND Review.

During the last year we have:

Responded to a range of national consultations, including Shaping Future Support: The Health and Disability Green Paper, the national Autism Strategy, and New Local Area SEND Inspection framework.

Provided a written response to the House of Lords Children and Family Act 2014 Inquiry.

Surveyed our members on the Down Syndrome Bill and Mental Health and Wellbeing.

Our wider Policy work

The NNPCF is a member of the Special Education Consortium (SEC) and Health Policy Influencing Group (HPIG).

This enables us to join other organisations who protect and promote the rights of disabled children and children with special educational needs.

The Government has made important commitments in Parliament that babies, children & young people will be an integral part of the Health and Care Bill, thanks in part to work by the children's sector's Health Policy Influencing Group.

Talking Points – NNPCF Key areas of focus

The Talking Points reflect our strategic priorities and shape our discussions with national partners. The Talking Points are reviewed annually.

Policy Briefings

Our regular Policy Briefings continue to keep parent carer forums informed of national policy developments.

Communication team

Richard Hobbs, IT and Communications Lead

Over the course of the pandemic and beyond, our communications channels, website, Facebook Twitter, and our staff WhatsApp, have become more important than ever as everyone continues to embrace the electronic way of working.

The communications team has worked hard to keep our members informed of the latest SEND developments and the work that the NNPCF has been involved with.

As our management team grows, so does our digital reach.

We have moved to a hybrid model of meetings, combining in-person meetings with the option of joining in via Microsoft teams. This has led to a continuing rise in meeting attendance as well as giving everyone a chance to try out the new technology

This continued with our two-part conference, with a choice of webinars offered to our membership. We had representatives from the DfE including Will Quince and our colleagues from Contact. Menti meter has been a fantastic way of interacting and quickly gaining people's views and has helped inform the work we do.

Finance and operations

Claire Powers, Finance and Operations Lead

We completed our transfer into our Community Interest Company, National Network of Parent Carer Forum C.I.C. (NNPCF CIC) this year and now have our own bank and HMRC accounts up and running.

Our Steering Group members became employees as we switched over to the CIC and our Management Team are now also employees with all having the option of a NEST pension.

We also put in place a HR system to further streamline our back office as we continue to work towards long-term stability and sustainability of the NNPCF CIC.

WHAT ARE YOU MOST PROUD OF?

Our Inclusive Park – Bedford Borough Parent Carer Forum

Following a period of feedback in Bedford Borough around the lack of inclusive parks for those with physical disabilities, Bedford Borough Parent Carer Forum applied for and were awarded £100,000 from Bedford Borough Council through the Mayor's Youth Empowerment Fund to help build an inclusive and fully accessible outdoor area of play.



Regional Annual Reports

East Midlands

Richard Jaramba

The East Midlands has shown great resilience in going through the COVID-19 pandemic. Parent Carers in the region played a significant role in the COVID-19 lockdowns by becoming teachers, home-schooling all children including the vulnerable, administering medications, providing safe social activities and treatment, and still managing to be essential workers and loving parents during the pandemic.

COVID-19 brought to life some of the disparities in the provision of SEND services. Reports and studies are still examining some of the long-term effects on the delivery processes and how to better prepare for pandemics in the future. The Pandemic in the East Midlands revealed the dynamic pressure of the regional population is diverse and located in some of the most deprived areas of the country and needs more and different provisions to meet the needs of the population.

Emerging from this pandemic, the regional leadership and local forums have shown strength and resilience. Forums in the East Midlands with new leadership have seen new challenges from campaign groups. In 2021 we welcomed Leicestershire's new forum, the Leicestershire SEND Hub, with new leadership led by Louise. Northants is growing and will divide which is in the planning stage. Derby City, Racheal and her team have been quietly focusing on the roles. Rainbow voices are now chaired by Jackie with a good blend in their leadership and are hard at work. Georgina, our regional chair has a focus on Derbyshire. Leicester City has come out of the longest lockdown period for any city in the UK, dealing with the pressure of their unique demographic and deprivation which is common to the region. We have a regional peer-to-peer challenge supporting forums and LAs in the region. The East Midlands, with a high turnover of leaders, has the challenge is training all Forums representatives in participation and the processes of co-production.

The inspections in the region have increased work to forums as they worked through WSoA and APPs. Nottingham passed their inspections, but their forum is showing extremely low parental satisfaction. Health provisions for post 16 have been cited in WSoA and the APP, adding work to forums in addition to the NHS E long-term plan. The Health Keyworker project has brought closer cooperation with Health, Social Care, and Education at a subregional level with LLR leading this work in the region. A member in our region stated, "Some LAs actions are worrying as they learn to satisfy the inspection process and not meeting the needs of children and their families."

The East Midlands forums would like to show appreciation to schools and the other essential services that proved to be a lifeline for families. Government information and procedures during COVID were given to families in ways they could understand through schools. Some schools managed to open when hospitals were shut, which is a tremendous achievement and shows the dedication to our children and society that is immense.

The East Midlands is slightly behind the West Midlands in some health projects. Our East Midlands parent participation is strong, and the East Midlands asked for capacity to help in some of the Autism in Schools projects in the West Midlands that are further ahead in their processes. I would like to thank you as a region for the strength to stand and keep the forums going through these challenging times. We emerge stronger together to share our common strength in our commitment to improving the outcomes of children.

East of England

Mrunal Sisodia

Like the rest of the country, for the East of England, 2021-22 was dominated by covid – the impact, the aftermath, and the recovery. Both families and parent carer forums continued to feel the strain for the whole year.

As the country emerged from the pandemic and services struggled to restore and recover, families reported a “tsunami of unmet needs” (Thank you to Sarah from Cambridge for such an evocative and accurate phrase). The causes and impact of this have been covered from a national perspective elsewhere in this report and I will not repeat them here. But we are all clear that covid is far from over and we are not back to normal. The hardships felt by families of children with SEND (Special Educational Needs and Disability) are greater than before.

Yet again, parent carer forums responded with determination, honesty, and creativity. Whether it was representing families let down by school transport, tackling the backlogs in autism waiting lists or challenging schools to make reasonable adjustments as children with SEND returned to schools, the forums in the East of England relentlessly represented the interests of families. This is despite continued and sometimes increasingly personal attacks directed at parent carer forums from some incredibly angry individuals. However, we continue our work and as we increase awareness of what we do, more and more families are joining forums, evidencing our continued importance to our communities.

Among all the difficulties, there were some notable successes to celebrate at a local level such as securing funding for new services and play areas, innovating new ways of reaching communities remotely, gaining representation on strategic boards, and setting up new parent carer forums – remarkable during the pandemic.

At a regional level, we have had great success in securing funding from the regional NHSE Learning Disability and Autism team. Our work on Admissions Avoidance was very well received by families in the region and other regional NHSE teams – bolstering awareness of dynamic support registers and the use of Care Education and Treatment Reviews. Regional pilots such as Keyworking and Autism in Schools commenced in some areas. We are being asked to participate in more and more regional programmes –underlining the impact and value of our contribution. And finally, we launched our regional website which you can find here: [The Eastern Region of Parent Carer Forums](#)

Finally, I have to say that I can take very little credit for any of this. I am supported by a phenomenal team in the region – the 11 forums provide fantastic intelligence on what is happening in their locality that allows our regional team of Karen, Sylvia, Jo, Sarah, and Philomena to do the hard work of representing the lived experiences of families.



London

Fazilla Amide & Ros Luff

The reported year proved challenging for our families, with COVID and its restrictions still persisting. However, many of our forums managed to resume face-to-face engagement. One forum reported they have seen better attendance with virtual meetings. Another forum promoted itself by providing schools with branded hand sanitisers.

The region conducted a pan-London survey to look at the impact of the third national lockdown on our families. The sobering picture showed that short breaks and therapy services had not fully recovered and some families were struggling with the return to school. We shared the report widely, including with DfE and ALDCS (Association of London Directors of Children's Services).

The London bid for the Autism in Schools project was successful; however, with a delayed start of February 2022, the project results will be shared in next year's report.

Pan-London events: In May, we met with two members of the DfE's social care team to help inform the social care consultation. The primary focus has been looked after children, but the representatives of the social care team very interested and impressed with the NNPCF focus group.

We met with the DfE advisors for an open Q&A session and for them to give an overview of their role.

We have continued as ALDCS' SEND Steering Group representatives (including presenting at their conference).

Our forums have been involved in a number of different engagement initiatives, including:

Camden: Parent Expert Session where a parent shares their experience on a particular theme or area and gives other parents their top tips.

Waltham Forest: Successfully advertised to new members – the advert was available in 10 different languages (translated by forum members) and was distributed by their new Parent Forum Champions.

Enfield: The forum received some LA funding for a parental wellbeing programme. Called Tree of Life, this programme was co delivered with the local Education Psychology Service.

Barnet: Ofsted inspection led to a request for the forum to deliver a training session on Co-production to CQC inspectors. Their good work was also referenced in the House of Commons, by the MP for Vauxhall.

Haringey: As a new forum, they co-produced their first information sharing event in partnership with the LA and SENDIASS for mainstream SEND families

Harrow: The forum ran online art workshops and their local Morrisons have provided craft materials and other goods

Lewisham: Coproduced with their LA, a very informative Parent & Carer Guide for the Local Offer

Some forums have faced major challenges (e.g., Croydon had a Section 114 placed on their area) with a need to reform themselves or replenish their membership. Some strong new forums/organisations are emerging, including Haringey, Greenwich, and Barking & Dagenham.

Several forums secured grants such as the PEARS grant and have used these for innovative outreach/engagement programmes. Engagement & co-production remain a mixed picture.

We would like to thank all of the forums, including those not listed, for their continued hard work and commitment.

North East & Cumbria

Jo Gilliland

Another busy year in 2021/22 for forums in the North East & Cumbria.

This last financial year saw an increase in our work to prepare for the changeover to Integrated Care Boards and a greater need for forums working collectively over the ICS footprint.

Our work in shaping the Keyworker offer in our region has gone from strength to strength and we are incredibly proud that we have parent carers from across our region, working within the early intervention aspect of our offer delivering workshops to families.

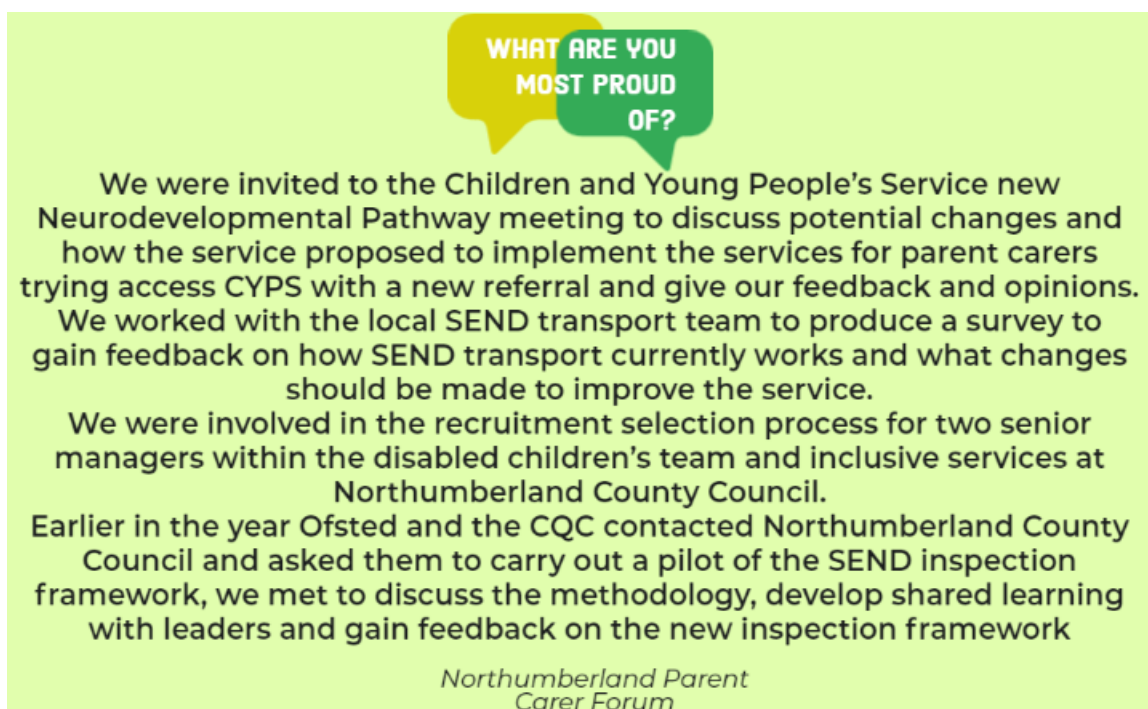
Our work on the Autism in Schools project continues and we are now active within 37 schools across the North East & Cumbria. We look forward to picking up more schools as we move forward with the project into 2022/23.

Forums continue to work hard and largely with a more blended approach due to the learning and new methods brought about by the pandemic. Many of our forums are looking to formalise their structures allowing them to diversify to meet the requirements of the local communities they are working for and with this, in turn, comes much work and dedication which is to be admired.

All our forums have now been through the local area SEND inspections and one area has been involved in helping shape the proposed new framework.

The commitment and passion from all of the forums in the North East & Cumbria have remained unwavering, and it continues to be a pleasure to work with all of the forums and their representatives. We look forward to building upon our regional representation and ensuring that we continue to have a strong representative voice across the entire ICS, which is no mean feat owing to the vast geography, making it the largest ICS in England.

A huge thank you to all of our forums, and I look forward to continuing our good work into the next financial year.



WHAT ARE YOU MOST PROUD OF?

We were invited to the Children and Young People's Service new Neurodevelopmental Pathway meeting to discuss potential changes and how the service proposed to implement the services for parent carers trying access CYPS with a new referral and give our feedback and opinions. We worked with the local SEND transport team to produce a survey to gain feedback on how SEND transport currently works and what changes should be made to improve the service.

We were involved in the recruitment selection process for two senior managers within the disabled children's team and inclusive services at Northumberland County Council.

Earlier in the year Ofsted and the CQC contacted Northumberland County Council and asked them to carry out a pilot of the SEND inspection framework, we met to discuss the methodology, develop shared learning with leaders and gain feedback on the new inspection framework

Northumberland Parent Carer Forum

North West

Kath Bromfield

The North West PCF's have worked tirelessly this year in the face of huge pressures created by Covid and the impact of lockdown within the North West.

They have worked locally, in our three distinct areas of Cheshire & Mersey, Greater Manchester, and Lancashire, and regionally in what is a large footprint.

April 2021 to April 2022 has seen all our 23 forums thrive with some new PCF's emerge and for the first time in many years, all PCF's claiming the DfE grant. This is amazing in times when capacity and energy is a challenge. It really needs to be celebrated.

We continued to meet virtually with those who needed to, and people valued that opportunity to navigate as PCF's together. The relationships and support systems that developed have been invaluable even as we reduced the sessions as more face to face returned.

As a region, we have held bespoke leadership training for some of our parent/carers. This is a direct intention to succession plan by the region and was a real success with lots of positive feedback.

We also have made our first regional video with a shared approach to bring together voices that can help individual forums but also help the professionals they work with and raise the understanding of how local PCF's link in with regional and national conversations.

We have co-produced the design of our Children's Board and work closely with our leads to ensure the voices of parent/carers within this work, linking in with NWYouth Focus to ensure the wider lived experience voice. This led to the region being instrumental in the North West getting funding to work with Contact, AlderHey and Edge Hill University around a Sensory Project. This has been a co-produced project at every level and is leading to new partnerships and we hope it will have benefits nationally.

All in all a busy and productive time regionally in a time of flux and change. We have started to meet each other face to face in this period and have treasured our time back together in person making sure we support each other into the next year with laughter and occasional tears.



WHAT ARE YOU MOST PROUD OF?

Doubling our members and engagement of parent carers in Halton with the help of our new mascot Sammy Sunshine.

We also started a new parent drop in service in connection with our CCG in all schools and nurseries across Halton.

Halton Send Parent Carers Forum HSCF

South East

Sarah Clarke

Yet another year dominated by the pandemic and its fallout, which has sadly seen even more of our families go into crisis and many more on the brink, struggling to access services, making the work of forums even more valuable.

The amazing work of the forums never ceases to amaze and inspire me. On top of all their own family SEND (Special Educational Needs and Disability) carer needs, all the forums have found time to support the SEND families in their area and continue to work on improving their local SEND services, as well as inputting into both the regional and national picture.

This year we have continued with our regular virtual meetings, shared our learnings and information, and supported each other. Resilience truly runs through every forum's veins. We developed and have started to roll out our training programme for the South East Region forums. Our relationships with regional Health and Local Authority partners have continued to grow and strengthen.

Many forums have even managed not only to survive, which is an achievement in itself, but some have also developed their work further (to name but a few) here are some of the South East's wow moments:

Family Voices Surrey – have secured additional funding for 3 years from their LA, coproduced videos explaining the EHCP process, enabled SEND CYP (Children and Young People) to access specialised swimming lessons for the same price as their peers, and ran a virtual event with the LA for SEND Early Years.

Reading Families' Forum – have worked tirelessly to save the local hydrotherapy pool for families, working on addressing equipment issues for families and concerns around CAHMS.

FACT Bucks – were one of the last areas to be inspected, coproduced Sufficiency of Specialist School Place strategy paving the way for a substantial increase in ARP and Special School places. Secured a doubling of Adviser resources for the SENDIAS service with whom they have a strategic partnership which included the production of a suite of webinars and agreed priorities for their shared engagement in strategic meetings.

East Sussex PCF - hosted two powerful sessions where parent carers shared their SEND experiences directly with Local Authority and NHS decision-makers to highlight what needs to change. Parent carers talked openly and honestly about some difficult experiences and local authority representatives were struck by the emotional impact felt by families of their often extremely challenging experiences. They are working with a local charity, Holding Space, to run monthly coffee mornings for parents & carers whose children were struggling with their mental health. Their membership continues to grow, helping them build up a 'bigger picture' across the county; they have recruited more parent carer representatives, and a steering group, made up of truly dedicated individuals, is now up and running.

West Berkshire – has become a totally independent PCF and is growing from strength to strength. The energy and drive of the forum is something to behold. We eagerly await what comes next.

Wokingham – have been involved in all the WSOA (written statement of action) working groups leading up to the revisit and also co-chaired the Coproduction group. Played a lead role in the production of a PfA Guide for Parents & Carers and produced a Local Offer Guide in place of our annual face to face event, both of these being very positively received by families. Their membership continues to grow, up 24% last year, and were also able to increase the number of events we ran for parent carers, which included a range of extremely popular SENDIASS training sessions.

There are lots of people to thank too, who have worked hard in supporting the region; Andrew Howard, FACT Bucks for Chairing the region; Julie Singleton our Contact Advisor; Holly Davis as our regional admin support; along with the Contact Advisors Fazilla Amide and Sharon Smith for supporting our training programme this year. And of course, by no means least, to all the forums in the South East for everything they do for each other and their forum families every day.

South West

Tina Emery

I started writing this report by looking back at all the other reports that I have written, not because I have forgotten what work we have done in the SW, but to remind me of the sheer volume of what we have achieved.

Last year we stood up for our young people who were facing the DNAR and the CFS and how forums in the SW quickly worked with all to resolve it, to this year again with NHSE SW getting funding. Which will allow us to do a regional project looking at children and young people's journeys, identifying the gaps, and looking at lessons learned and how we can feed that into a training programme.

We have succumbed to the pressures of the parent carer forum world, by losing 3 forums this year. However, very quickly, because of the tenacity of parent carers wanting to make a positive change within their local communities, we have regained our losses very quickly and we are now back to 15 forums. We welcome the new forums in BANES, Torbay, and the Isles of Scilly.

Our work is being recognised on the national stage, not just for how we communicate and work with NHSE SW, but also the work we produce together.

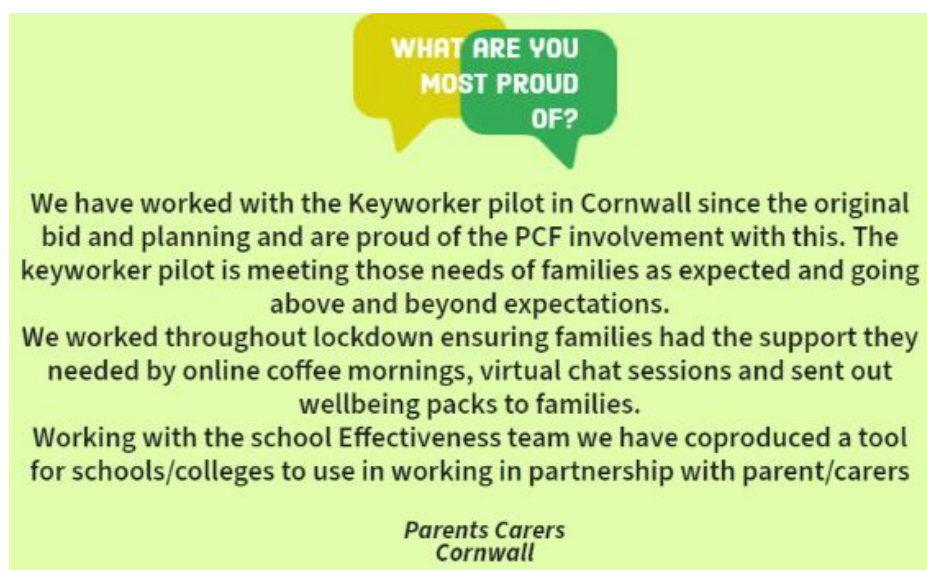
We developed a regional admission avoidance booklet, we then developed one for every southwest STP footprint. The regional booklet was picked up by NHSE national team and to date, despite no national communications being done with the booklet, we have had nearly 3000 views. Each local document has had views, and we did that. It sets out to families, what they can do themselves to prevent an admission into a tier 4 bed.

Work with the autism in schools project has been busy and the work continues, but it has been well received. Bournemouth, Christchurch, and Poole started first and ran with it, covering the whole school approach starting at pre-diagnosis of what autism is, as well as training staff and informing young people with peer-to-peer sessions.

The Isles of Scilly were next, co-producing the training that will be delivered on the Islands, so it will be as unique as them, with an emphasis on community training, not just limited to the school, with a look to train the parents as train the trainers through AET Cornwall, so that this programme has longevity. Cornwall has just started their journey as I write this report, but with the PCF chairing the steering group, I have no doubts that the programme will be a success.

The success in the SW is down to how we work as a team, we achieve together, because we work together. The 15 forums in the SW work tirelessly to get better outcomes for all families. We are supported as a region by Sue Mennear, Kate Hurn from Contact, Ruth Hobbs in Somerset as our regional admin, and Kay Henry in Cornwall, who helps to look after our Facebook group.

Without you we could not do it, so thank you!



West Midlands

Elaine Lambe

2021/2022 for the West Midlands was a year dominated by the pandemic and changing leadership of the region.

In February 2022 we said goodbye to Zara Bowden as our NNPCF regional representative after many years in the role. We thank her for her tireless work to ensure that the voice of the West Midlands Parent Carer Forums was heard both regionally and nationally. Elaine Lambe (Warwickshire) took on this role with big shoes to fill. We also said goodbye to Sue Mennear as one of our region's Contact Advisors and thank Cindy Bayliss for her continued support.

During 2021/2022 the West Midlands Parent Carer Network continued to meet virtually about once a month giving the opportunity for all the West Midlands forums to come together for mutual support and to share their successes and challenges. This year Sarah Thomas and Sally Anne Keane stood down from their roles as Co-Chairs of the Region and Micki Stimpson left her role as Regional Admin – we thank them for their many years of work in the Region. Heather Delany (Solihull) and Zara Bowden (Shropshire) have taken on the role of Regional Co-Chair.

It has been a difficult year for many forums – Birmingham's Local Area SEND reinspection hit the national headlines for all the wrong reasons and many other areas have had to write Written Statement of Action or Accelerated Progress Plans following their inspections / re-inspections, sadly One Voice Coventry closed its doors leaving the area without a forum and limited representation across their local area, we look forward to working with Contact to encourage a new forum in the city.

However, there are many things to celebrate – last year we saw new forums in Sandwell and Warwickshire with Dudley becoming independent of their host and this year we saw them grow in strength and confidence making a difference in their local areas.

Highlights from our forums include:

Solihull holding a SEND community event and managing to get the widest range of professionals and parents in a room along with local councillors to focus on working together in Solihull.

Telford and Wrekin using the evidence of the need for more family support in the home from their annual survey to work with their educational psychology service to develop twice monthly support sessions where parents can discuss home / life concerns, seek information and advice from the educational psychologist team and find solutions together in a safe and supportive place.

Warwickshire is being praised by their Department of Education Advisor for their tireless work to improve coproduction in the county following the Written Statement of Action.

Regionally we had two Autism in Schools projects running which involved forums working together (Stafford, Stoke, Shropshire and Telford, and Wrekin in the north of the Midlands and Birmingham, Solihull, Coventry, and Warwickshire in the south) across their health footprints and we look forward to the extension of this work in the year ahead.

WHAT ARE YOU MOST PROUD OF?

PODS Parent Carer Forum

Educational Psychologist Support Sessions

In 2020 and again in 2021 we produced an Annual Survey report which evidenced the need for more family support in the home. Needs identified includes peer support, support for family around challenges in the home around their child's anxiety, behaviours, routine, relationships with siblings, etc. It was also apparent that those children who were on the waiting list for neurodevelopment pathways needed more support.

Through conversations we had at the time to understand the role of the Educational Psychologist service, we highlighted a gap in service provision and agreed that we would write a proposal which was taken to Aiming High for SEND Board. The proposal was shared with our families and with the team of Parent Reps.

We used a 'solutions-focussed' model of engaging with the families, and whilst this was a new way of working, it was soon embraced.

The support offer, was led by PODS who administered the events and organisation, gathered feedback from families and built a case for further development of the offer, based on this. It has led to an offer of 1:1 sessions for families with more complex situations. Continuation of funding for another two years of the 'sessions' has recently been agreed and will be funded by health.

Yorkshire & Humber

Jayne Fitzgerald

As across all regions, Yorkshire and Humber families living with SEND find themselves very much in the throes of post-pandemic turmoil. For many of our families, lockdown brought little difference in terms of isolation and accessing services needed. However, what it did highlight was the incredible resilience and passion for working in partnership to get better outcomes for our children and young people.

Despite the turmoil and the experience of some families that suddenly ALL children were regarded as the same, despite needs, and the anxiety experienced by some children and young people being lost in new policy, the Yorkshire and Humber Regional forum came together stronger to form a new structure that can reach as many of our families as possible and ensure their voice and experience is central.

Restructure:

- This year we have held monthly meetings, bi-monthly online, to ensure that the opportunity to feed in member experience and each area contributing to regional decisions is there.
- Regional policies to support the restructure, election of roles and recruitment, code of conduct, finance, and constitution. All written by subgroups, open to the whole region, and signed off at regional meetings.
- Co chairs, interim admin, and treasurer have been elected.
- Voice of members on their priorities gathered bi-annually and presented to regional SEND leads and NHS leads meetings. This already coming to fruition in identifying joint priorities, emotionally based school avoidance and home to school SEND transport policy.
- The region was successful in getting the priority grant from Contact to support our restructure as a region.

Moving forward we are focusing on effective communication via SharePoint, WhatsApp, admin role, training, and at the request of forums looking at formal forum-to-forum support and the mechanisms to do this. 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. Working together as one community made up of all local areas, the priorities from forum discussions regarding participation and partnership with services are:

- working with Integrated Care boards and the opportunity to share lived experience and keep it central to developments
- the cost of living crisis and its very real impact on our families who are often doubly disadvantaged
- the re-engagement of members post covid to widen the voice locally and regionally.

We celebrate and welcome 2 new forums in the region, East Riding and Barnsley. We also look forward to welcoming Leeds in the coming months, who are in the process of reforming with Contact support.

There are so many ways that individual forums are making massive strides and making a difference for families, in a recent poll, 12 out of 14 forums are in formal and close contact with both the SEND lead and designated medical officer in their area.

The unrelenting work and passion that goes into making a difference to families through our forums daily is phenomenal and gives us reason yet again to be proud of Yorkshire and Humber, despite the blocks and hurdles, the often heartache we are hearing and witnessing, we take the next steps together. We recognise that we can't do this alone and need each other which is why our focus has been on structure and developing mechanisms to ensure that lived experience is at more tables across our region and plays a part in developing services for our families.

Thank you to every family, every forum, regional forum, and national colleagues at NNPCF for all you have brought this year, together we really do make a difference!

What are you most proud of:

How the region has come together to support one another and to develop the restructure putting families central to our coproduction work x

A very small group
of Parent Carers
starting up a PCF
in B&NES.

WHAT ARE YOU MOST PROUD OF?

Family Voice Calderdale held their Annual Conference & AGM in March 2022 and it was in person after the restrictions of the pandemic. It was enjoyed by both parents & professionals who came together to exchange ideas and network.

The theme of the Conference was Better Information, Better Outcomes and included a workshop session looking at ways to improve the Local Offer.

Parent Carers said they found it both enjoyable, informative and felt motivated to act.

As a result a new Steering Group was formed at the AGM with 10 new members



Blackburn with Darwen Parents in Partnership

We held our Disability Information Day in March 2022. This is an annual event, but this year we pulled out all the stops to make it bigger and better, as we knew that our families had really missed being able to interact with services during the pandemic.

Our NHS Links and DCO were instrumental to the days success, as they put out a "call to arms" message and as a result health services were very well represented at the event.

We also relied heavily on our steering group and volunteers, they worked super hard on the day signing visitors in and serving refreshments.

We had over double the amount of visitors, including groups from days services, special school and college, and we had 65 stands on the day.

The event increased our profile both within the community and also with education, health and social care services.

It was an absolute achievement to be able to present the annual conference with the Local Authority this year after having an absence of 2 years due to the pandemic. North Lincs Parent Forum are very proud to say that they are very much involved in the strategic level of planning with the North Lincs Council. They sit on the SEND Strategy Board and work at the developmental stage of any plans and support the council with parent led consultations to support the feedback for the parental voice.

North Lincs PIP forum

In such tough times WarrPAC have continued to grow and increase our voluntary team. We recruited two new volunteers this year who are both enthusiastic. They give their time and commitment to support and engage parent carers in Warrington.

Another huge achievement for Warrington is after many years of one of our parent representatives sitting on the Carers Partnership Board, she finally got Parent Carers added to the Carers Strategy and recognised as Carers by Adult Social Care

Warrington Parents and Carers

West Sussex Parent Carer Forum

This year we have nurtured a great relationship with Chichester University! We regularly join their classes of trainee teachers and SENCOs to share our journeys as parent carers, discussing examples of good and poor practice that we have encountered. We have found that sharing real experiences directly at this stage makes a bigger impact than any textbook could, and really brings home the importance of trust, empathy and collaboration with parents - a message which will make a huge difference to the work of teachers and SENCOs.

It has been such a success that we have been asked to do the same for social work trainees too!

We are excited to create a legacy of true coproduction that will improve the daily lives of SEND families.

Hull Parent Carer Forum
Breakfast Clubs!

We used our Seldom Heard monies to host regular Buffet Breakfast meet ups we named Breakfast Club to reach a more diverse group of parents who had previously not been involved for various reasons being hard to reach.



Halton Send Parent Carers Forum (HSCF)

We started a Family Craft and Pizza night for all parent carers and children. This is so successful it will run again this year. It has been a great post covid event for everyone to establish friendships, improve mental health, improve isolation, making sure children have a good meal and much more. We currently have a waiting list in advance of publishing these dates.



From the start of the pandemic we started to realise that parent carer wellbeing was becoming increasingly important so we started to look at ways we could help with this. We were given funding from Bedford Borough Council to train 4 Steering Group members to deliver the Healthy Parent Carer Programme. The Healthy Parent Carer Programme is designed to improve parent carers' health and wellbeing by promoting emotional balance through understanding, empowerment, confidence and resilience. The best thing about the Healthy Parent Carer Programme is that it is delivered by parent carers so there is always an element of understanding.

Bedford Borough Parent Carer Forum

What will the next 12 months bring?

At the time of writing (November 2022), our plans for the end of 2021-22 seem hopelessly out of date.

In April, we were gearing up for a major round of engagement on the SEND Green Paper, preparing for our response to the consultation, and looking forward to working with the government on its implementation.

Since then, however, we have seen three Prime Ministers and five Secretaries of State for Education. This turmoil has meant that we do not know what will happen with the three most significant policy areas we have been working on – the SEND and AP Green Paper, the Schools Bill, and the Review into Children's Social Care.

Instead, factors such as the cost of living crisis, energy bills, and the continued pressures on the NHS have increased in priority for forums.

For the NNPCF, this has led to a shift in the focus of our work – as engagement on the SEND Green Paper has receded, we have prioritised the work that is ongoing that will make a difference to families of CYP with SEND here and now – for example, the roll out of the NHS Long Term Plan including the Autism in Schools and Keyworking initiatives and engaging in the Delivering Better Value in SEND programme to ensure it focusses on the right things.

As for local forums, we recognise just how tough things are for families with SEND at the moment. You have shown your resilience and flexibility time and time again but please make sure that you look after yourselves through these difficult and unprecedented times.

But most of all, keep doing the brilliant work you always do – representing families, asking difficult questions, and coproducing better solutions.

Because, it is only through participation and coproduction that we can improve outcomes for our children.



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