

# PARENT CARER PARTICIPATION 2019 – 2020

TRANSFORMING LIVES

Delivery partner of



Department  
for Education

**contact** *For families  
with disabled children*



## CONTENTS

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The impact of Parent Carer Forums	<b>6</b>
Strategic engagement of forums	<b>10</b>
Reaching seldom-heard groups	<b>12</b>
Contact: supporting Parent Carer Forums to change lives	<b>20</b>
Funding the forums	<b>25</b>

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# WE ARE CONTACT, THE CHARITY FOR FAMILIES WITH DISABLED CHILDREN

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Contact has been supporting families of children and young people with Special Educational Needs and Disabilities (SEND) for over 40 years.

A decade of austerity and the hugely complex education, health, and social care systems reducing the availability of, and access to state and charitable support for families, comes at a time when the population of disabled children has grown by a third. In 2020, Contact launched an ambitious 3 year strategy driven by digital transformation and co-production, and underpinned by 5 guiding aims:

1. We will be the first charity for families to turn to when they find out their child has a disability
2. We will double the number of families we support through our high-quality information and advice service
3. We will drive social change, raise more money, and support more people – by helping families feel more connected to Contact
4. Families will shape our work, so that they get the local help they need in the ways that work best for them
5. We will develop a sustainable business model that ensures Contact is here for families with disabled children into the future.

## SUPPORTING PARENT CARER FORUMS

Since 2008, Contact has provided 151 Parent Carer Forums (PCFs) in England with the resources to operate and develop, offered enhanced support to areas with challenges, and administered the annual DfE grant enabling PCFs to work alongside local authorities, health and other partners to influence, design and co-develop services for children and young people with SEND.

During 2019-20, Contact's Parent Carer Participation team provided 5,184 hours of direct support, resources including bespoke webinars, access to a wellbeing programme via CiC, and governance support to the 113 PCFs registered with Community Matters Yorkshire. PCFs are members of the National Network of Parent Carer Forums, working together to influence regional and national policy and legislation. This annual report highlights the impact that PCFs made to services, and the lives of children and young people with SEND and their families during 2019-20.

For more detailed information and resources to support Parent Carer Forums visit: [www.contact.org.uk](http://www.contact.org.uk)



# A WORD OF THANKS

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2019-20 had been going so well with the DARE Resilience course rolled out across the regions and two cohorts of the Leading your Forum course completed. We produced a pilot Seldom Heard toolkit to finetune with forums next year. Many forums responded to our survey on support and what they would like to see in the future, and we began to think big, planning for a future contract. Then in early 2020 the Covid-19 pandemic hit, events had to be cancelled, and in March, the country went into lockdown. What followed, we have never experienced in our lifetime. The pandemic changed everything as we knew it, as if the lives of parent carers weren't challenging enough!

Contact salutes all forums, the regional networks, and the NNPCF steering group and national reps who have been working so hard to represent the views of local forums and families nationally, ensuring that parent carer forums remain high on the agenda. You are an inspiration!

**Carolyn Deveney, Head of Parent Carer Participation, Contact**



This year, despite unexpected challenges, forums have continued to explore new ways to engage families. They have ensured the

voices of parent carers are heard, listened to and most importantly, acted on to make the differences families say matter most. Their commitment is evident in the Ofsted/CQC Local Area Inspections where they've made sure the experiences of families are central to conversations. I have had the immense privilege to support the work of parent carer forums for many years and their resilience, tenacity, and desire to make things better for others continues to make me hugely proud to work alongside them.

**Gail Walshe, Director of Participation and Regional Development, Contact**

*“Contact salutes all forums, the regional networks, and the NNPCF steering group and national reps who have been working so hard to represent local forums’ and families’ views nationally. You are an inspiration!”*



# THE IMPACT OF PARENT CARER FORUMS

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Parent Carer Forums are the go-to groups for local service providers seeking evidence and case studies from families with children and young people with SEND.

## MAKING A DIFFERENCE AT LOCAL INSPECTIONS

This year, parent carer forums have been involved in all aspects of the Ofsted/CQC SEND Local Area Inspection process. They have been there:

- *from preparation for inspection and peer review*
- *during the inspection week*
- *in follow up meetings, and*
- *if their local area received a Written Statement of Action (WSOA).*

Some were also involved in the preparation for, and during the revisit following a WSoA.

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**46%** of forums who were inspected during the year felt that the inspection workload was manageable.

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Of the areas still preparing for inspection during 2019-20:

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**50+%** of forums felt that the additional workload was manageable

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Contact and the NNPCF have been working alongside Ofsted, CQC and other stakeholders to determine what a future inspection framework will look like.

## PAINTING THE FULL PICTURE

The involvement of parent carer forums in the inspections ensures that inspectors gain a full picture of the impact of local services and provision on the families receiving them. Parent carer forums highlight what is working well and where improvements need to be made. They bring evidence from surveys of families, reports, case studies and anecdotes to the process. This information coupled with the webinar and survey data (for revisits) is both insightful and powerful.

## CREATING WORKABLE SOLUTIONS

The evidence from the lived experience of parent carers, and the solution-focused way in which forums work in co-production with their service partners enables workable solutions to issues to be found and actioned. It also enables providers to deploy scarce resources in the places where they are needed most. Contact continues to gather success stories and case studies from forums on how their work has made a difference in their local areas – you can read some later in this report.



96,969

parent and carer  
members – a  
9.6% increase on  
last year



62,419

forum members  
shared their  
knowledge and  
experiences via  
drop-in sessions,  
surveys or  
consultations or  
social media



1,159

forum members  
were directly  
involved in  
running the  
forum or in  
organising parent  
participation  
work



177,089

parent carers  
reached online



## **SHROPSHIRE SEND LOCAL AREA INSPECTION**

Parent and Carer Council Shropshire (PACC) had been proactively working with the local authority to raise awareness of the impending SEND local area inspection. The forum was instrumental in developing the Shropshire SEND Strategy and actively sought parental feedback into its development. The result was that families were able to clearly articulate what good would look like for them during the inspection. The forum had surveyed parent carers and had ongoing conversations with the local SEND community so that they could produce a succinct report ahead of the inspection on the 'State of SEND' in Shropshire focusing on the key issues and areas that required improvement. This was sent to the lead inspector and shared with the LA and CCG. PACC worked with local agencies to promote the inspection to parent carers and tell them how they could get involved, including the parent webinar, and also promoted the inspection via their own social media channels and website.

During the inspection, PACC attended all relevant meetings which was a significant commitment. PACC presented at the opening meeting where the inspection team was introduced, and the self-assessment was shared. PACC led the self-inspection presentation, introducing the forum, its strengths, and challenges, and presented some of the issues in the State of SEND report. It was the first time that the lead inspector had seen a Forum lead the self-assessment presentation.

7 parent carer reps from PACC held a meeting with the inspection team. PACC also set up an open meeting for Shropshire parent carers to meet the inspectors and ensured that everyone had read the State of SEND report as the focus would be on the key issues it contained. More than 30 parent carers attended.

Shropshire was issued a Written Statement of Action, which PACC felt was the right outcome. PACC was pleased that the inspection letter reflected the issues that parent carers had highlighted, and especially pleased that the lack of effective co-production in the local health sector was recognised, along with the need for improved strategic leadership. PACC's work and the important role they play was acknowledged in the inspection letter, and by local partners. PACC is now fully engaged in the WSoA and joint statement of intent underpinning its development and delivery. The priority is to ensure that Shropshire parent carers are kept informed re progress, and that their voice remains central to this work.

**Parent and Carer Council Shropshire**

## **NORTH SOMERSET PARENT CARERS FORUM'S RESPONSE TO THE SEND LOCAL AREA INSPECTION**

The SEND local area inspection in 2018 highlighted that parent carers were overwhelmingly negative about their experiences of services and support. The majority felt that they were not listened to by officers and told inspectors that they had 'been let down by the service' or, have to 'fight' to get their child's needs assessed to secure timely and appropriate support. North Somerset Parent Carers Working Together was supported by Contact to respond to the findings by building strong relationships with parent groups and partners, and to find a new way of working going forward.

Contact encouraged the forum to apply for a discretionary grant. The forum used this for leadership training to strengthen the committee and help parents take on key roles in the forum; and to fund events to bring together different groups and stakeholders to improve services for children with autism, a local priority area.

Contact's Associate training helped the forum and partners to agree a Local area Co-production Charter and SEND strategy outlining how they work together. A 'Together is Better' agreement was developed between support organisations helping ensure a joined-up approach in the best interest of the local SEND community. North Somerset Parent Carers Working Together also applied for funding to gather evidence and make a case for funding from the LA and CCG to help ensure the forum's sustainability. They successfully secured funding from both the LA and CCG.

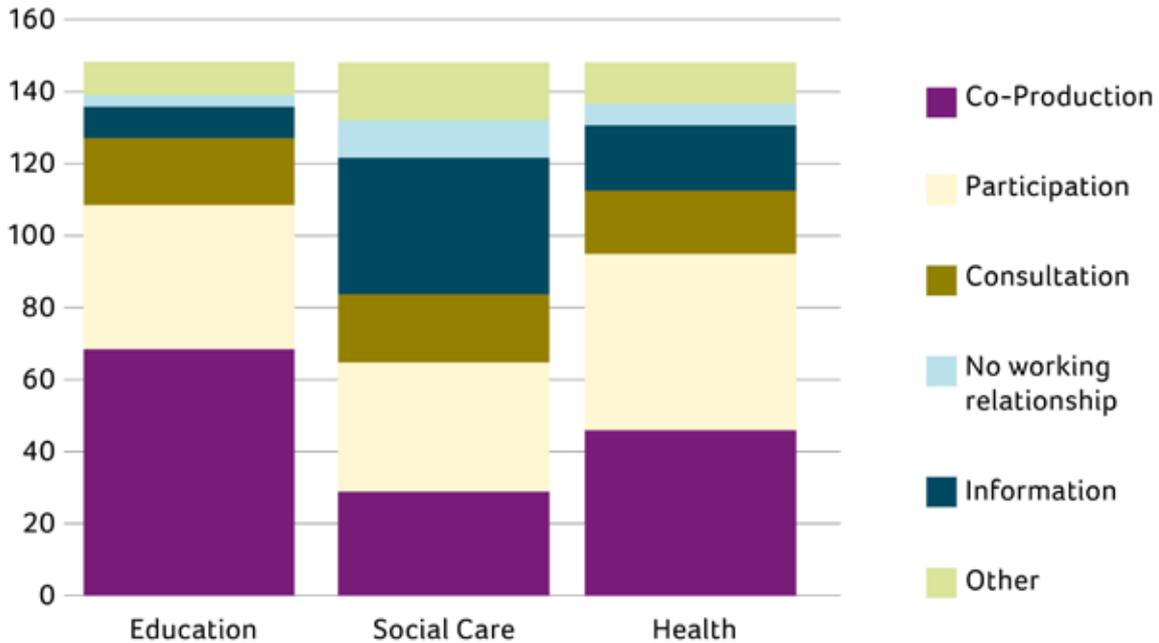
The forum now reports that that stakeholders, including North Somerset Council and BNSSG clinical commissioning group, show a clear commitment to co-production and are listening to parents. Additional support and funding have resulted in a strong sustainable forum that is a respected strategic partner and has strong relationships with other groups in North Somerset giving parent carers an effective, collective voice.

### **North Somerset Parent Carers Working Together**



# STRATEGIC ENGAGEMENT OF PARENT CARER FORUMS

**Forum relationships in 2019/20**



## WORKING IN CO-PRODUCTION

Parent Carer Forums continue to play an active role in local, regional, and national co-production. Co-production occurs when all partners have an integral and equal part in decision-making processes and are fully engaged in shaping, developing, implementing and evaluating services and systems.

In 2019-20:

**66** forums reported working in co-production with their education partners, which shows a healthy increase from 53 in 2018-19.

## Education leads the way

Parent Carer Forums continue to have greater co-productive relationships with strategic Education partners than with their counterparts in Health or Social Care.

## INVOLVEMENT IN SEND INSPECTIONS DURING 2019-20

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46 forums reported involvement in their local area's preparations for their Ofsted/ Care Quality Commission SEND local area inspections.

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96% of those forums involved were either fully or partially involved in the inspection or re-visit.

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### How involved was the forum in the inspection/re-visit process



# REACHING SELDOM-HEARD GROUPS

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## **SELDOM-HEARD TOOLKIT**

During 2019-20 Contact worked with Include ME Too to develop a toolkit to enable forums to reach out further into their communities and give them the confidence to approach different groups demonstrating the appropriate cultural sensitivity. Something that many forums have said that they struggle to do.

## **WORK DURING COVID-19**

Work to take the toolkit out to other forums to test and seek their feedback for further development has been delayed due to the pandemic, but is firmly on our agenda to take forward. We want to bring the toolkit to life with examples of how forums have successfully reached out and engaged more widely.



# BRIGHTON & HOVE PARENT CARER FORUM

## REACHING OUT FURTHER

Through their strategic work, Brighton and Hove PaCC became aware of more seldom heard groups of parent carers including Traveller families. The forum contacted *Friends, Families and Travellers* (FFT), a local organisation supporting traveller families who reported being aware of high numbers of families with children and young people with SEND who struggled to find out what support was available to them. The forum was also aware that many Black, Asian, and minority ethnic families were not engaging with the forum, and if PaCC wanted to represent all SEND families in the city, they had to change that.

### Creating accessible information

Through their work with FFT, PaCC was made aware that adult literacy was an issue, so, in conjunction with traveller families, PaCC and Amaze designed and produced an easy read version of their forum flyer containing pictures and key information and numbers that families could call. In collaboration with FFT, PaCC organised an informal information session at the local permanent travellers' site. They were able to inform traveller families about the forum and left some flyers. In addition to making travellers' families aware of the forum, their work with FFT also raised their awareness of PaCC, and they could refer families to them.

### Reaching out to more families

PaCC also asked Black, Asian, and minority ethnic families what they could do to engage more families. They consulted them through informal one to one interviews, and a focus group. It was suggested that PaCC translate their leaflets and do more outreach at Black, Asian, and minority ethnic families community events, so PaCC started taking their flyers to

different locations and community centres and met families at events and through coffee mornings. More and more Black, Asian, and minority ethnic families became aware of PaCC.

### Linking with local parent support groups

The forum's outreach work connected them with a newly formed parent carer group, *Fresh Youth Perspectives* who among other things supports parents and carers of children of all races who have been marginalised or excluded from school. The group became a PaCC Partner.

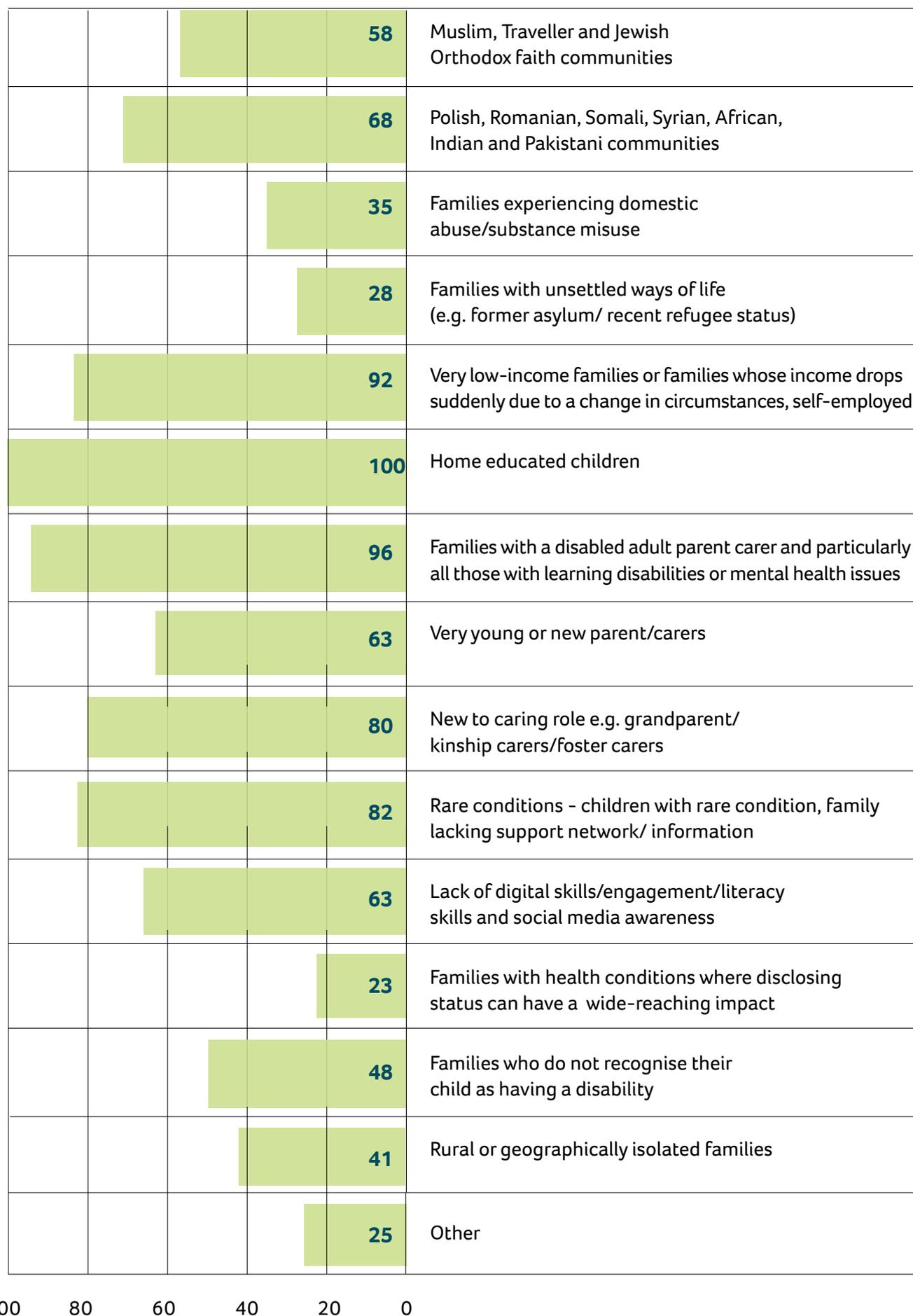
More recently a parent carers group, *A Seat At The Table*, whose main aim is to empower Black, Asian, and minority ethnic families parents and their children by supporting ways to forge developing their identity and or understanding of their SEND, has joined PaCC as a partner.

Representatives from both groups regularly attend PaCC Steering Group meetings.

[paccbrighton.org.uk](http://paccbrighton.org.uk)



## Which of these groups has your forum successfully engaged with in 2019/20?



# INFLUENCING NATIONALLY

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## **NATIONAL NETWORK OF PARENT CARER FORUMS**

All Parent Carer Forums in England are members of the National Network of Parent Carer Forums (NNPCF). The NNPCF, as an umbrella organisation representing parent carers' voices nationally, strives for the best policies for children and young people with SEND and their families across local areas, regions, and England-wide. The NNPCF works closely with the Department for Education, the Department of Health and Social Care, NHS England, Contact and other partner organisations to fulfil their aims and objectives, which are 'better services and improved outcomes for children, young people with SEND and their families'. The NNPCF also ensures that local Parent Carer Forums are connected, networking, and aware of national developments, consultations, and opportunities to shape policy.

## **NATIONAL RESPONSE TO COVID-19**

During 2019-20, NNPCF steering group members, who are also members of their local Parent Carer Forums, contributed 798.5 days of their time influencing regionally and nationally on behalf of their members. This figure was 59.7% above their annual target. Similarly, the NNPCF's National Representatives contributed 112 days of their time, 12% above their target number of days. The spike in activity during March, as the global pandemic hit, truly demonstrated the value placed on the NNPCF and Parent Carer Forums by Government, local authorities, and health organisations.





# 2019-20 SUCCESS STORIES

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## **WOLVERHAMPTON – CO-PRODUCTION**

In October 2019, Voice4Parents and young people from Wolverhampton Challenge Board co-produced a SEND Visioning Day ‘Spotlight on SEND’. Parents, carers, and young people led on the day which saw over 100 people come together and included families and service providers sharing their experiences of what was working well and where improvements could be made. Feedback from the day, responses from Voice4Parents annual survey, findings from the JSNA and SEND Health review are now being shaped into the City of Wolverhampton’s SEND Strategy which will define priorities for delivery over the next 5 years.

### **Developing a co-production charter**

Wolverhampton has a Co-production and Communication group which includes representatives from different partners across the City, and Voice4Parents, that is helping to drive and embed co-production. The City recently launched its Co-Production Charter, a set of values and principles of working together to ensure families remain at the heart of discussions and decisions. These values have been developed with young people, parent carers, City of Wolverhampton Council; Royal Wolverhampton Trust, and Wolverhampton CCG; Wolverhampton Voluntary Sector Council and Wolverhampton Information, Advice and Support Service.

### **Adopting the charter**

The Charter has been adopted by the Children and Families Together board and wider Council, which will really help to embed co-production across the local area and change

the culture of how families, and practitioners work together to shape services and improve outcomes.

### **Changes afoot**

The approach is already changing how services are shaped in Wolverhampton. There has been a real increase in publicity and communication with families and many people are talking about it; the forum is helping to publicise the Charter across Wolverhampton. Co-production is being put into practice both strategically, and with individual families.

### **Next steps**

A set of outcome measures and resources will be developed that will support practitioners and services to embed this way of working, including a tool kit/how to guide, self-evaluation, and case studies showing what can be achieved. There are already some positive examples of how the Charter is making a difference.

### **Wolverhampton Parent Carer Forum**





## **DORSET – IMPROVING SERVICE DELIVERY**

Dorset is a large rural county. The SEND local area inspection highlighted that there was work required to increase the confidence of parent carers. Dorset Parent Carer Council worked closely with local service providers to make the necessary improvements, though they struggled for capacity and funding. Due to the additional work involved, they made a successful case for increased funding to the LA for a paid co-ordinator and applied for a discretionary grant to help to increase their capacity. They ran Expert Parent Training which has helped them recruit new active members, increase their capacity and to become a charity.

### **Increasing confidence**

The forum introduced ‘Parent Panels’ a bank of willing volunteers to help with the design and delivery of different pieces of work. The Participation Coordinator has provided new steering group members with a mentor/buddy to support them to attend strategic meetings, which has increased parents’ confidence and the number of reps coming forward. The forum is now more resilient as an organisation

and is increasingly being recognised as a strong strategic partner and collective voice of parent carers.

### **Improving partnership working**

This approach led to improvements in service delivery across Dorset. Parent carers were instrumental in ensuring that the Dorset IASS became a commissioned service with a business plan informed by the parent carer voice and not just by quality standards. There is a shared aim to create a Memorandum of Understanding between the forum and SENDIASS which will improve partnership working and the service to families.

### **Valuing all voices**

The forum identified that families were unhappy with key statutory elements of SEND in Dorset these included Annual Reviews and the EHCP template. Working together with young people, parent carers, SENCO’s, EP’s, schools, colleges, and early years, SEND team, and health and social care, a new EHC plan template and Annual Review process are now in place. Parent carers have also been central to creating a development and behaviour pathway and involved in the tendering process for short break provision for children and young people with SEND.

### **Dorset Parent Carer Council**



# CONTACT: SUPPORTING PARENT CARER FORUMS TO CHANGE LIVES

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Contact helps to empower parent carer forums to influence local, regional and national services and legislation. We provide access to the annual DfE grant and support forums with their day-to-day running

## **GIVING FORUMS THE SUPPORT AND INFORMATION THEY NEED**

Contact is the lead partner for the strategic participation consortium working on behalf of the Department for Education and alongside the NNPCF to support the development of parent carer participation, and the Council for Disabled Children and KIDS who lead on the strategic and local participation of children and young people with SEND.



## **HOW WE DO IT**

We provide a core offer of support for each parent carer forum including a dedicated Parent Carer Participation Adviser who forums can contact to access phone and email support to help them to run their forum effectively.

### **Sharing information**

We keep forums informed and updated, via our website, with regular joint newsletters with the NNPCF which provide vital information and guidance for forum members, as well as success stories from other forums to demonstrate the impact that forums have on service development across the country.

### **Bespoke support**

For forums experiencing challenges, we have a pool of skilled and experienced Associates to provide bespoke or intensive support. Our website is packed with resources for forums at each stage of development including a suite of webinars designed specifically for forums.

## **WHAT FORUMS SAY ABOUT CONTACT**

In 2019-20:

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**100%** of forums said they were 'very satisfied' or 'satisfied' with the support received from their Participation Adviser

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**98.6%** of forums were happy with how Contact dealt with their enquiries about the grants process.

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## PRAISE FOR CONTACT'S SUPPORT THIS YEAR

*"The support I have received from all of the above has been excellent. I always receive prompt and clear advice when requested and there are never any problems. A pleasure in fact."*

*"The service from Contact is excellent as always. Knowledgeable, experienced, friendly, professional and always available. They are a great source of practical advice and a great support."*

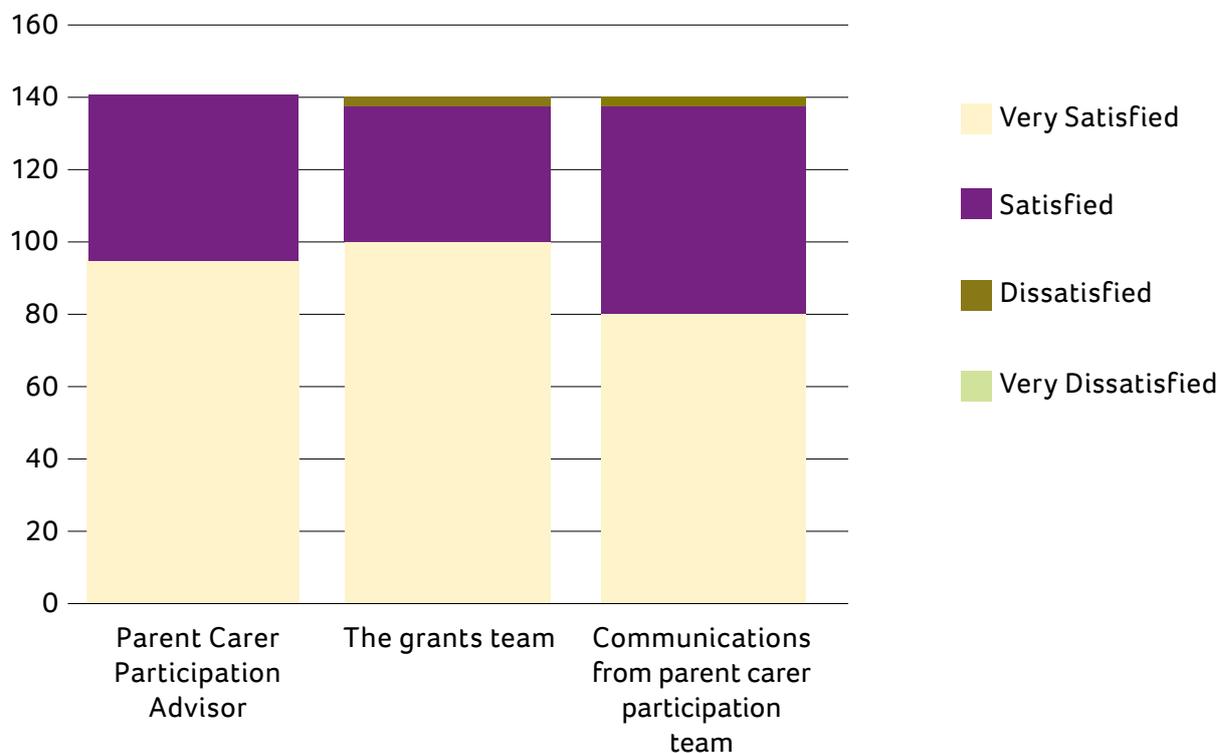
*"Our Parent Participation Advisor is ALWAYS on hand when needed; she is always extremely helpful and supportive."*

*"Our support from Contact is always very helpful and prompt. If we have a question it is answered in an effective, friendly, timely manner."*

*I am so grateful for the service and support from Contact at every level and interaction. I feel supported and enabled to make my Forum a success."*



### What forums thought of Contact's support in 2019/20



## LEARNING

Contact provides learning and development opportunities to all Forums, equipping members with the skills needed for them to make a difference.

During 2019-20, Contact delivered 9 webinars:

- *Support around grant monitoring and applications*
- *Transforming care*
- *Learning disability GP annual health checks for over 14's*
- *SEND support – what does it mean for your children*
- *Using technology to support your Parent Carer Forum*
- *Using the media to reach more parent carers and amplify your forum's message*
- *What does the Long-Term plan mean for Parent Carer Forums*
- *Learning disability and autism in the NHS Long Term Plan and*
- *Nuts and bolts: A library of resources to run your forum.*

All webinars were developed and delivered in partnership with forums, external partners or experts in the field on the topics that forums wanted.

### Flexible learning

During 2019-20 we reached more than 1,300 forum members across all English regions. The beauty of webinars is that they can be watched live allowing for some interaction and questions, or forum members can watch at their convenience once the recordings are uploaded to Contact's YouTube channel.

## FEEDBACK FROM PARENT CARER FORUMS

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100% of live attendees stated that they would recommend Contact's webinars to other parent carer forums

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93% of live attendees rated the webinars' usefulness and gave the webinars an overall rating of 4 or 5 on a scale of 1 to 5 (with 1 being poor and 5 being excellent).

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### WHAT PARENT CARERS TOLD US

*"Brilliantly engaging and interesting - I learned lots!"*

*"Really useful and gave us some more tools to consider in the future. Thank you :)"*

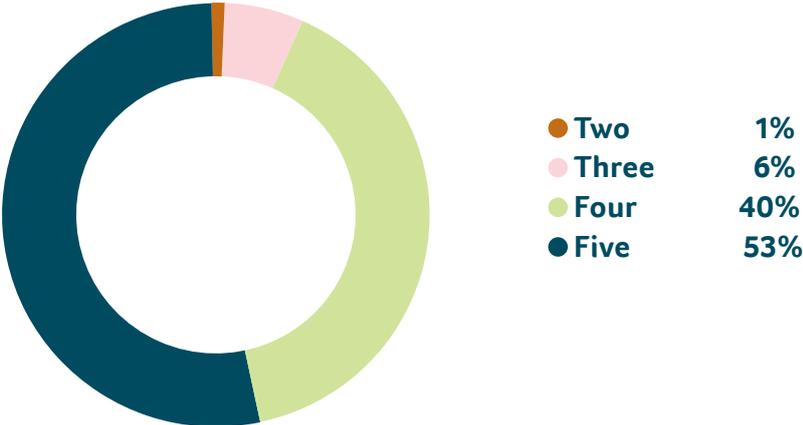
*"Very helpful to get slides. There was a great deal of useful content but too much to take in or follow up during the webinar itself. This is not a criticism!"*

*"Thank you, this was our first webinar and it was very informative."*

*"Easy to access and to join - I always recommend them and use past ones as a refresher."*

*"Really well presented and a lovely caring introduction."*

Overall, how would you rate the webinar?



# FUNDING THE FORUMS

## A CHANGING LANDSCAPE

Earlier in the year and before the Covid-19 pandemic took hold, Contact surveyed parent carer forums to find out what support they value most and couldn't be without, and what support they foresaw themselves needing in the longer-term as we moved towards the end of our current contract. Following lockdown, and events since, forums' needs are now different as the pandemic has taken its toll. We will work with forums to establish their essential needs prior to the re-tender later in 2020.

## CREATING SUSTAINABLE FORUMS

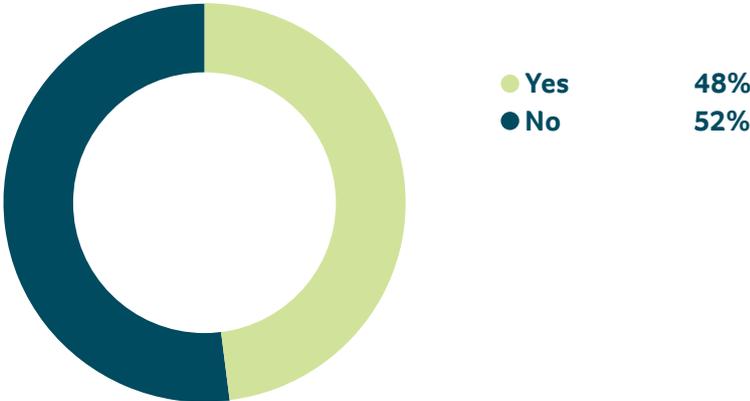
Contact and the NNPCF are continuously striving to seek an uplift of the current forum funding to reflect the work that forums do, the huge increase in work with health agencies, and the additional work and pressures that the SEND local area inspections demand, on forum members' time, and on forums'

finances. For forums to be sustainable, to enable their continued development and growth, and for them to be able to suitably recognise the involvement of their members, they require increased investment.

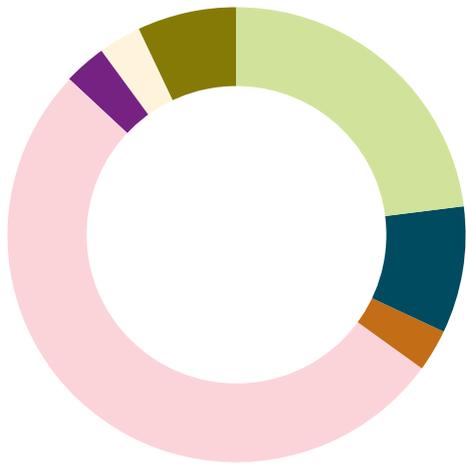
## ADDITIONAL FUNDING

During 2019-20, 48% of the forums who have so far submitted their 2019-20 grant monitoring received additional funding from alternative sources, totalling £1,799,120. The average amount of additional funding per forum in 2019-20 was £26,074. Local authorities remained the primary source of additional funding, with just over half of forums receiving funding from their local authority alone. Almost a quarter of forums received funding from their local authority and health, and a further 9% from the local authority and other funder.

**Did the forum receive funding to support parent carer participation in 2019/20 (other than the DfE grant)?**



## Sources of additional funding



● Big Lottery Fund/other charity only	23%
● Both local authority and charity	9%
● Both local authority and health	3%
● Both local authority and other	52%
● Health only	3%
● Local authority only	3%
● Other	3%



*“Forums have ensured the voices of parent carers are heard, listened to and most importantly, acted on to make the differences families say matter most... their resilience, tenacity, and desire to make things better for others continues to make me hugely proud to work alongside them.”*

**Gail Walshe, Director of Participation and Regional Development, Contact**





We are Contact,  
the charity for  
families with  
disabled children.

We support  
families, bring  
families together  
and help families  
take action  
for others.



## GET IN CONTACT



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