

# PARENT CARER PARTICIPATION 2021 / 2022

STANDING FIRM AFTER ANOTHER CHALLENGING YEAR





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Delivery partner of



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

One million children in the UK have a disability – and there's a desperate lack of services and support for them and their families. Parent carers face a huge range of challenges, from financial strain to securing the right education for their child. Many feel isolated, stressed and anxious every day.

We're here to make life better for all families with disabled children:

- ***We support families with the best possible guidance and information.***
- ***We bring families together in local groups and online, to support each other by sharing experiences and advice.***
- ***We help families to campaign, volunteer, fundraise and shape local services to improve life for themselves and others.***

Last year we supported 182,000 parents with our vital information and advice. This included 11,000 parent carer enquiries dealt with by the parent advisers on our helpline, 4,757 people who attended our parent carer workshops and 3,413 enquiries and one to one appointments managed by our By Your Side team who work with families in hospitals around the country. 738 children and 969 parent carers also attended our family events which aim to combat isolation by bringing families together face-to-face or online, to build networks, connections, and reduce isolation.

## SUPPORTING PARENT CARER FORUMS

Contact led the Department for Education's (DfE's) Strategic Participation contract ensuring the participation of parent carers and children and young people with SEND in local and national policy and service development with our consortium partners The Council for Disabled Children (CDC), KIDS, and the National Network of Parent Carer Forums (NNPCF). Contact has supported the development of Parent Carer Forums and administered their annual DfE parent carer participation grant over the last 14 years.

Contact's Parent Carer Participation team provided 6,029 hours of support to Parent Carer Forums who continued to champion the needs of others and support parents locally who were struggling with the aftermath of the pandemic, reflecting their views and experiences in meetings with local strategic partners.

For information on Contact's support offer for Parent Carer Forums, visit the participation pages of our website: [www.contact.org.uk](http://www.contact.org.uk)

## A word of thanks



It's been another year fraught with challenges which have impacted on families and Parent Carer Forums (PCFs) alike. The cost of living and energy crisis and resulting steep rise in inflation has created more stresses for families already struggling to get by and has created strain on forum budgets too. I am certain that Contact, PCFs and the National Network of Parent Carer Forums will continue to impress upon decision-makers the impact this is having on families of children and young people with SEND.

The last few years have tested the resilience of forums, whose members have enough personal challenges to contend with before running the forum. The selfless actions of forum members now will influence services for current and future families. But, as a wise person once said, remember to put on your own oxygen masks first, or you can't help others – look after yourselves too.

Forum membership has grown and there are now officially over 110,000 members involved in PCFs, and many more follow forums on social media. This is an amazing achievement. The case studies within this report highlight the valuable work and the difference that forums make in their local areas. Thank you to each and every parent carer involved in their PCF, past, and present.

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



This annual report marks the 14th year that Contact have supported and worked with Parent Carer Forums to amplify the voice and experiences of those caring for a disabled child. A lot has changed in that time, we've seen governments and ministers come and go but the determination of Parent Carer Forum members to speak out about the impact policy and funding decisions have on them and their children remains steadfast. It isn't always easy to put yourself forward to challenge and be challenged and I know very well some of the difficult situations some Parent Carer

Forums find themselves having to navigate, but persevering to build trusting partnerships that go on to make real differences for local families is why the persistence is worthwhile.

This report shows that co-production with parent carers is continuing to strengthen and that despite the impact of external factors, 105,637 parents gave their time and energy in 2021/2022 to make a difference for families like theirs.

Contact and the Parent Carer Participation Team are very proud to still be working alongside Parent Carer Forums and to share the same ambition of embedding a culture of co-production in every local area of England and across central government. We know that co-production is the key to better decision making and spending limited public resources right first time.

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



## The current landscape

This year the Government published the long-awaited SEND Green Paper. We now await the outcome of the national consultation response and hope that this takes into account the countless views raised by the National Network of Parent Carer Forums (NNPCF), forums, young people via FLARE and the Collective, and organisations such as the Disabled Children’s Partnership and Contact, to name but a few.

Charities, the NNPCF, and families agree there are a number of elements of the SEND Green Paper proposals that are very concerning, that might make it even harder for disabled children and parents to get the support they need. Ministers must use this time to ensure that any future changes to the SEND system really do work for children and families, putting their needs centre stage.

Every month that passes risks disabled children slipping further back in their progress. There are steps the government should be taking now – in particular improving accountability to ensure the system works as it should for disabled children and their families.

### DEALING WITH THE KNOCK-ON EFFECT OF THE PANDEMIC

Covid has not gone away, yet it is rarely mentioned as the country navigates political and financial uncertainty. While some of us saw a slow return to normality in 2021/2022, many families caring for a child or young person with SEND continued to deal with the knock-on effect of the pandemic. Health and support services failed to return to pre-Covid levels and thousands of children continued to miss out on their education, either because of school staffing issues, they were still shielding, or children were struggling to get back into a school routine. At the same time the impact of an emerging cost of living crisis began to take hold.

### SUPPORTING PARENTS IN A CHALLENGING LANDSCAPE

Many Parent Carer Forums have navigated the last two years of challenges and maintained their local presence, highlighting to service providers the extended impact of the pandemic on children and young people with SEND and their families. For some forums, the added pressures and strains were too much, and we have seen forums fold, and new forums develop in this time. Despite everything, there are almost 1,000 more parent carers involved in running their forums than at the same time last year.

### IF YOU ARE NEW TO PARENT CARER FORUMS

For anyone new to Parent Carer Forums over the last year Lewisham Parent Carers have produced a lovely [short introductory film](#) for anyone thinking of joining their forum. It conveys a simple, yet powerful message about the benefits of joining a Parent Carer Forum.

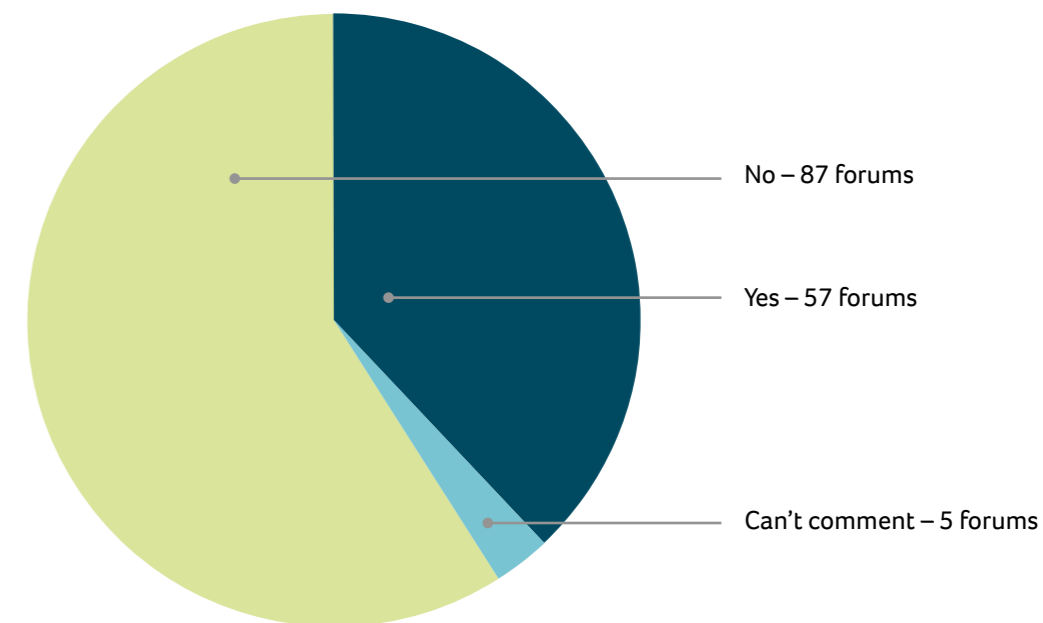
## The difference that forums make

### SUPPORTING LOCAL SEND INSPECTIONS

Local area SEND inspections and revisits carried out by Ofsted and the Care Quality Commission resumed and the remainder of areas yet to be inspected under the old framework took place, with many areas being revisited to gauge progress towards their written statement of action. Parent carers continued to be involved in the process via parental surveys and by meeting the inspection teams. Preparations for the new framework for 2022-23 continued.

Many local areas continued to work virtually where possible to keep costs and time to a minimum. Many regions have maintained virtual network meetings, with some resuming face to face meetings where appropriate and safe to do so. The NNPCF continued to work with government departments influencing policy and the SEND Review being part of the overall governance board. It has been a challenging and incredibly busy year.

Has your area been subject to a SEND inspection, interim visit or revisit by Ofsted and CQC this financial year?



# Our year in numbers



The forums have  
**110,551**  
 parent and carer members  
 breaking through the 100,000  
 mark for the first time



**105,637**  
 parent carers shared  
 their vital knowledge  
 and views of services  
 via drop-in sessions, surveys,  
 consultations and more,  
 providing crucial views to  
 help forums influence local  
 decision-makers



**2,231**  
 parent carers were  
 directly involved in  
 running the forum  
 or in organising parent  
 participation work, an  
 increase of almost 1,000



**1,542**  
 parent carers represented families strategically  
 in local meetings with service providers and partners



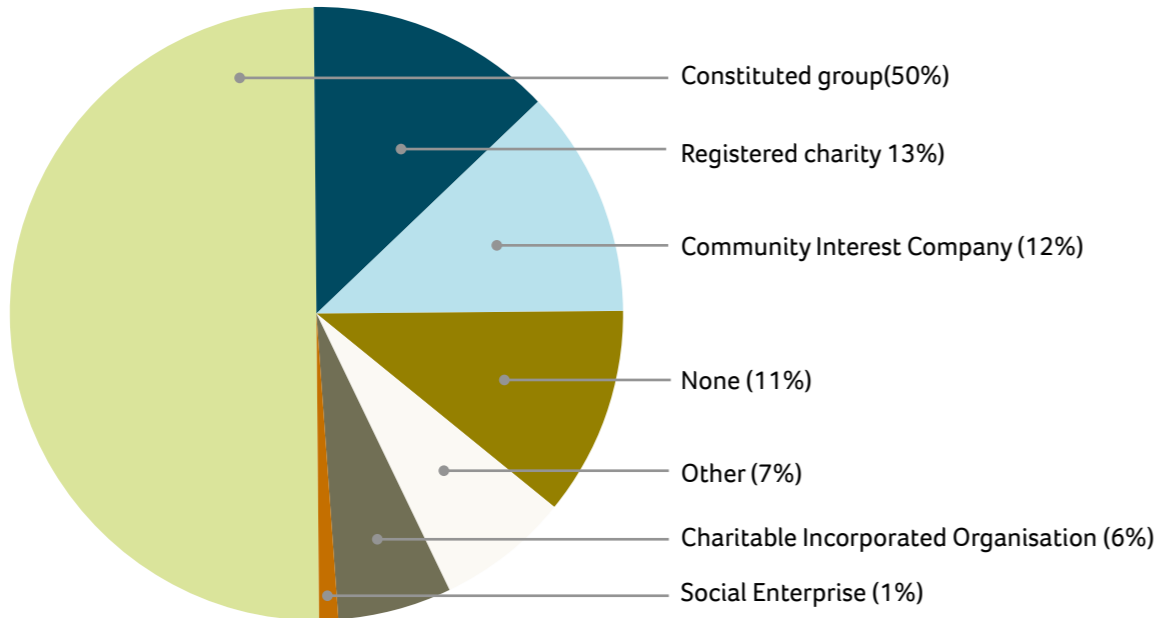
Forums online reach increased significantly, to  
**316,446**  
 an increase of 81,570 (34.73%)  
 demonstrating the increased virtual reach  
 of Parent Carer Forums since the pandemic

## FORUM STRUCTURES 2021/2022

Forum structures have largely stayed the same as during 2020-21. Whilst half of forums are constituted groups, there has been a small

increase in the number of forums becoming Community Interest Companies and a slight drop in those that are registered charities.

Forum status

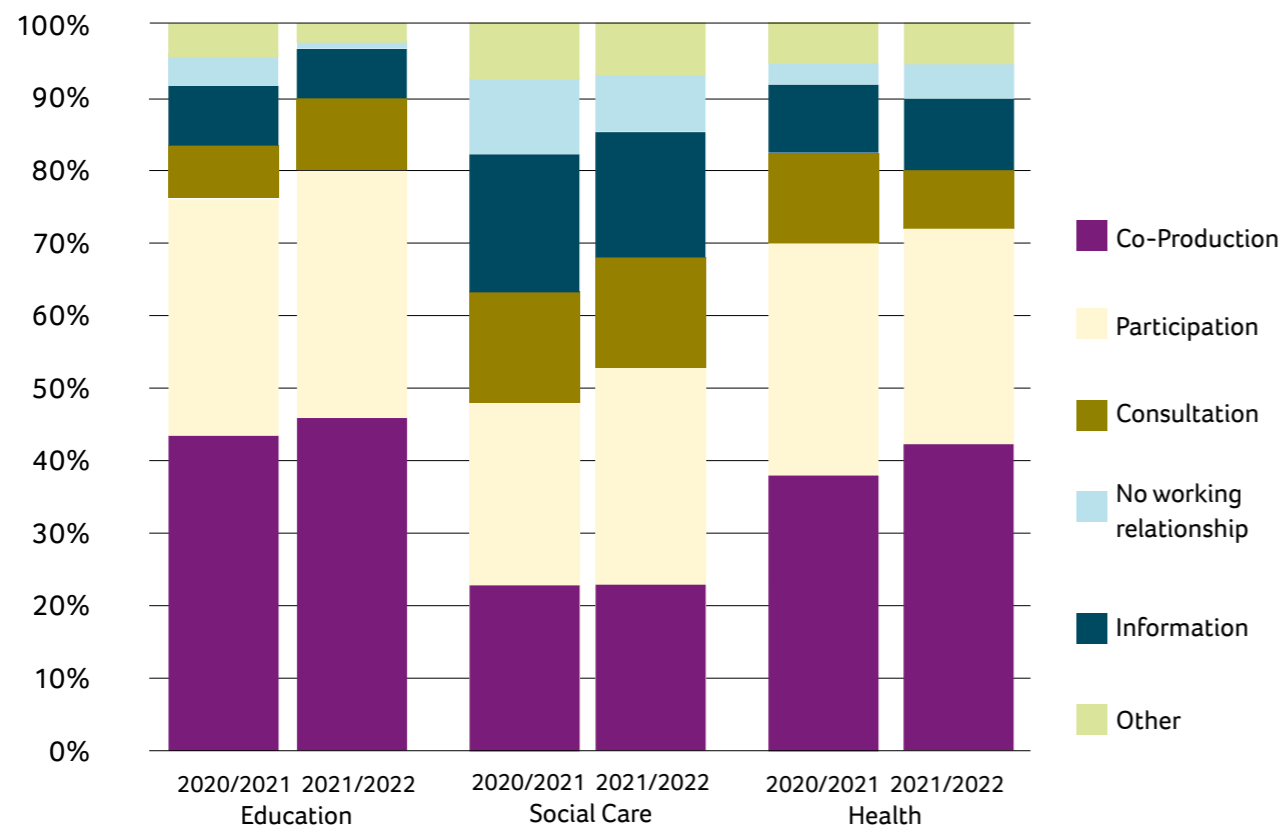


# Strategic engagement of Parent Carer Forums locally

Forums reported a slight increase in co-production with their education partners during 2021/2022 with 46.3% of forums (up from 43%) saying that they co-produced with education partners during the year; a further 34% of forums felt that they were participating with their education partners. 23.1% of forums were co-producing with social care, down slightly from last year and

a further 30% forums were participating. 40.8% of forums are co-producing, and 30.6% are participating with health partners. Only one forum had no working relationship with education and few forums had no working relationships with local health partners. As in 2020-21, more forums were not working with social care than with education or health.

Choose an item which best describes your relationship with:

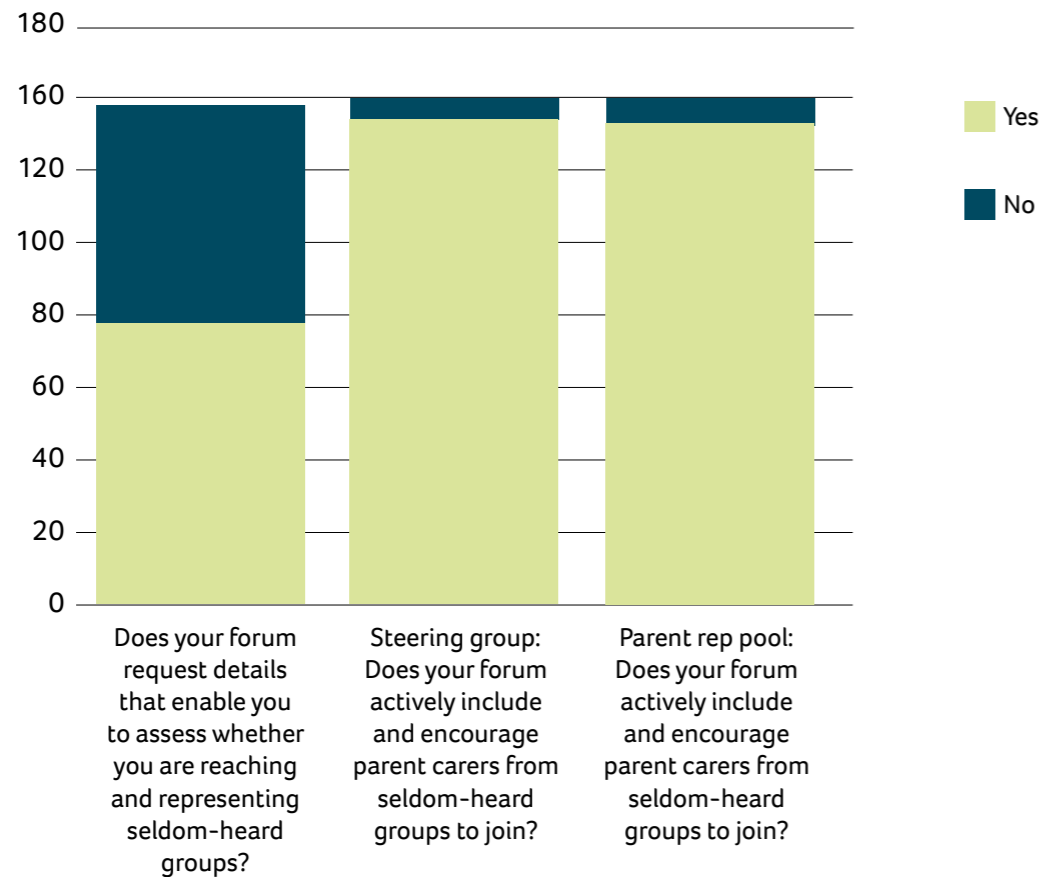


# Reaching diverse and under-represented groups

To be representative and to capture the views and experiences of all families, Parent Carer Forums need to reach all communities within their local area. To do this, they need a welcoming, inclusive culture. Many forums are proactively reaching out to engage underrepresented and underserved groups to ensure that their voices are heard, yet there is more work to be done.

Half of forums request information to help them to learn if they are reaching families from all areas of their local community; with 92% saying they actively encourage diverse representation on their steering groups, and 90% encouraging parent carers from diverse groups to join their parent representative pool. 52.7% of PCFs have an equality, diversity and inclusion (EDI) policy in place with 5.5% having a plan; but over 24% of PCFs have neither an EDI policy, or plan.

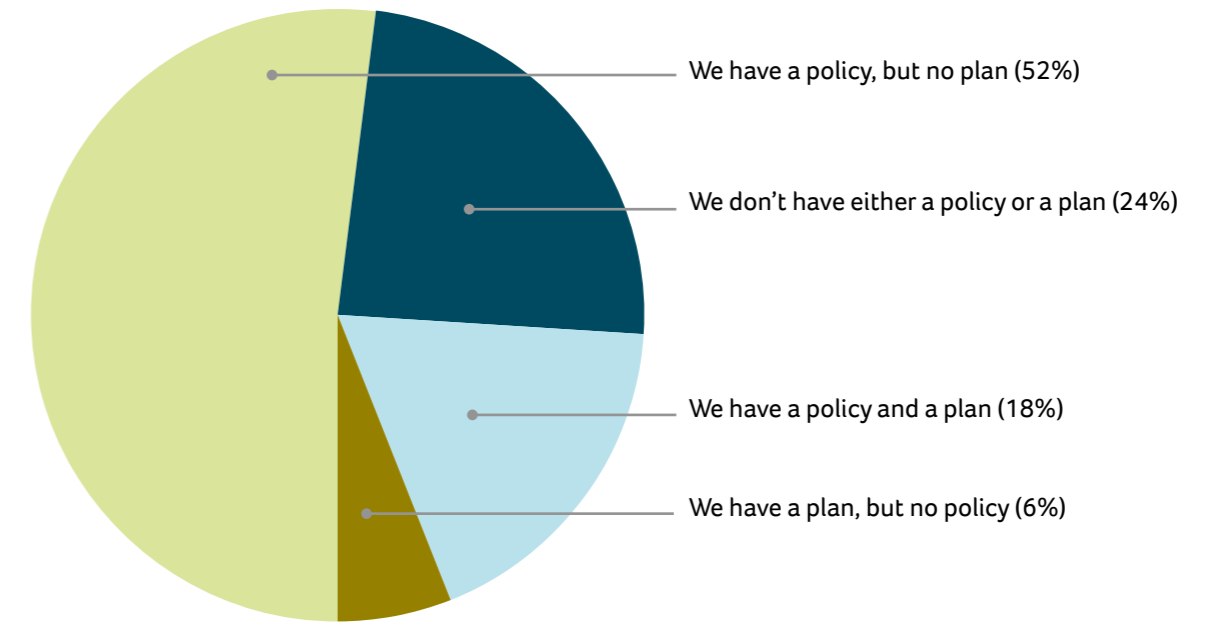
## Reaching seldom-heard groups



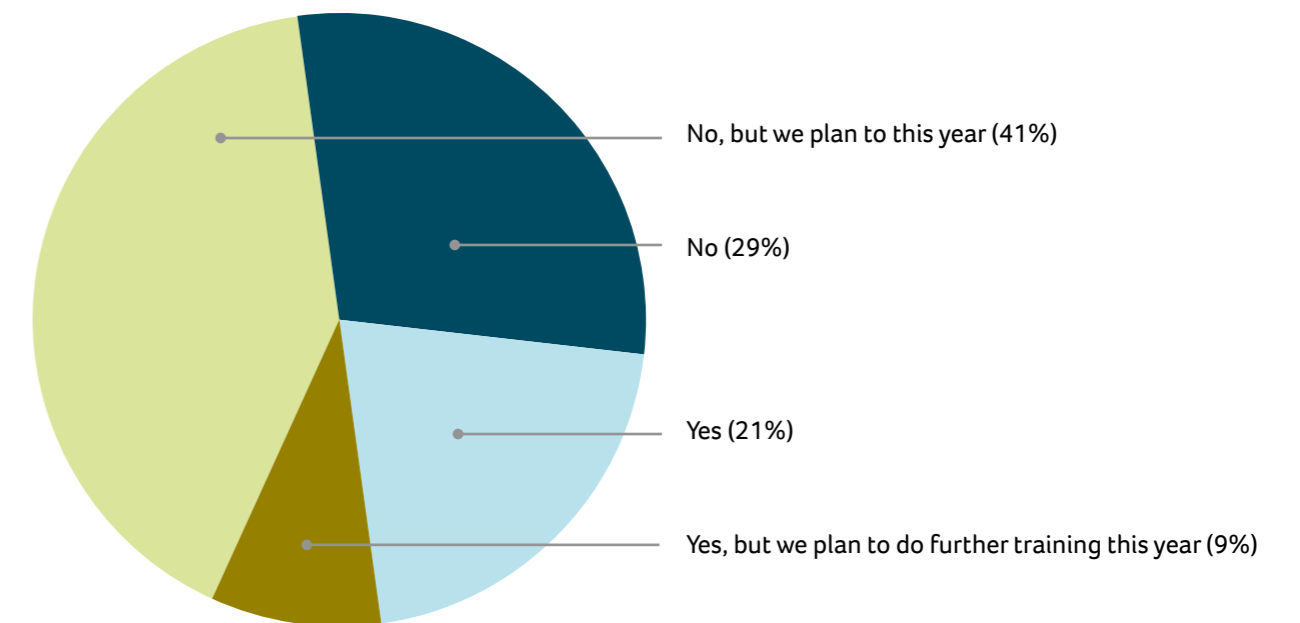
Contact launched an Equality Diversity and Inclusion (EDI) toolkit at the 2021/2022 joint annual conference. We also produced two template Equality, Diversity, and Inclusion policies which forums can tailor and use. We will offer further learning and support to help forums to ensure inclusive and welcoming cultures next year and we will be offering EDI training for all PCFs.

In their grant monitoring just 21% of forums reported that they had received EDI training, with a further 41% saying that they plan to attend training during 2022/2023. Contact plans to produce a summary version of the Diversity and Inclusion toolkit during 2022/2023 that will help forums to put on inclusive face-to-face and online events.

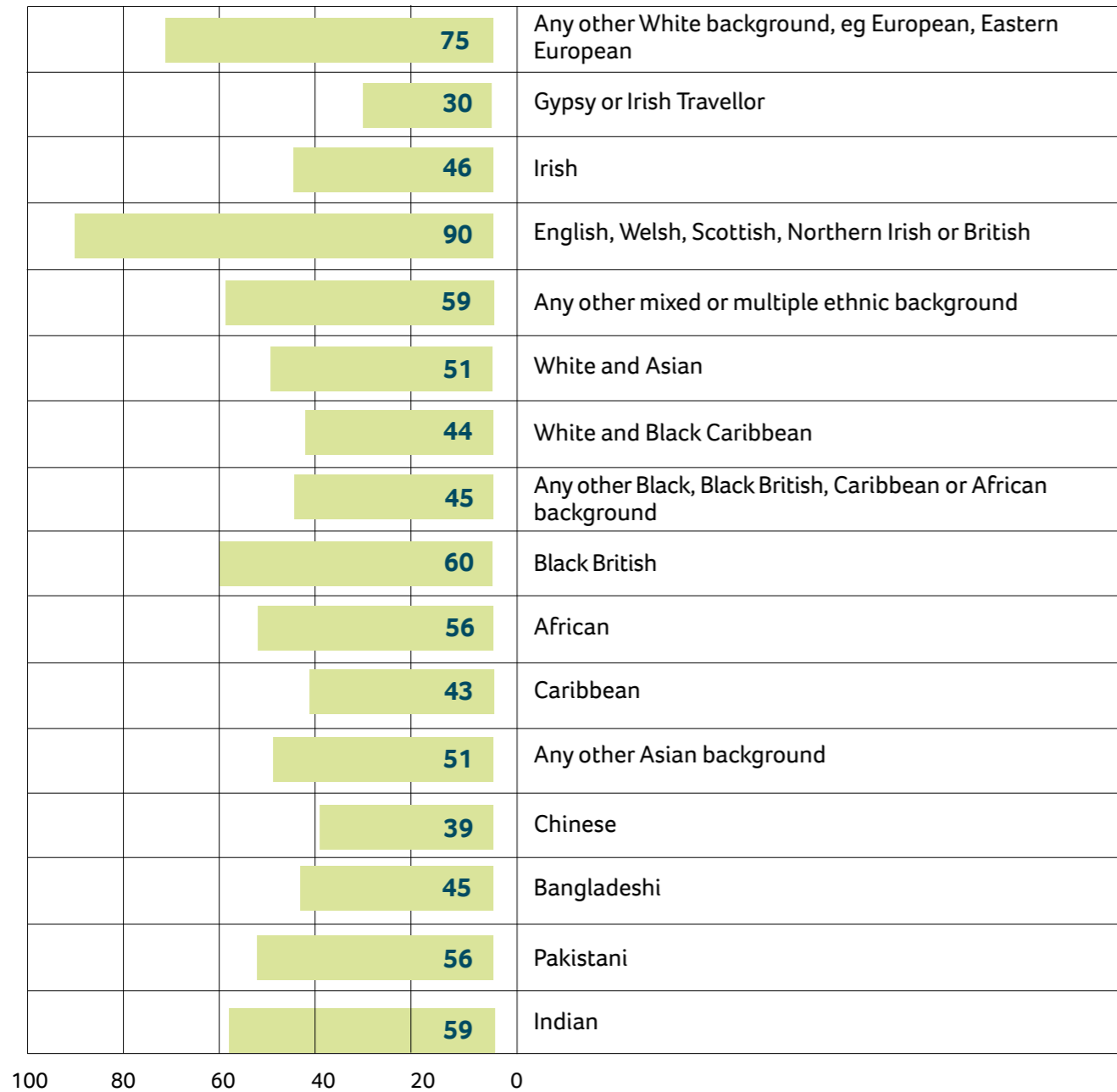
## Does your forum have an Equality, Diversity, and Inclusion policy and plan in place?



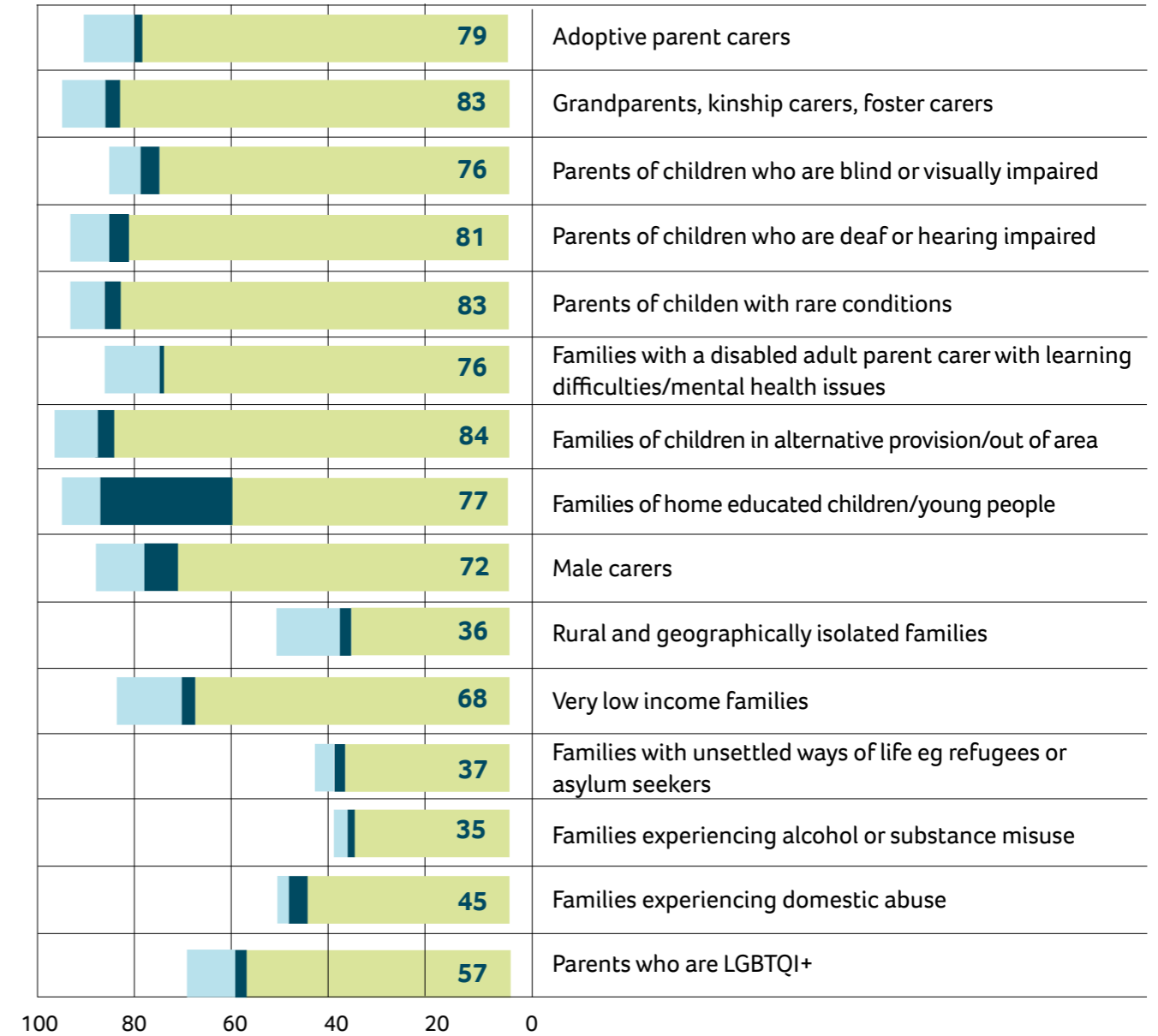
## Has your forum steering group attended Equality, Diversity, and Inclusion training?



The number of forums that are engaging with under-represented communities or groups



The number of forums that are engaging with under-represented communities or groups



- Yes, we are reaching and engaging this group
- We have carried out specific activities to reach out and engage with this group
- Yes, we are reaching and engaging this group / We have carried out specific activities to reach out and engage with this group



# Forum success stories



## CITY OF LONDON PARENTS

### A SEND Sports & Leisure Project for children, young people and their carers in the City

Although there were inclusive sports and leisure facilities in the city, some children were not able to take part because of the way these were offered. Parent carers were concerned about the lack of options and a consultation confirmed the lack of opportunities for SEND families.

City parent carers wanted a small range of specialist sports and fitness options just for SEND children, young people, and carers.

#### Consulting parents

Using parent carer feedback, the forum took up the challenge and started initial talks with the Leisure Centre and London Sport.

Through consultation and research, the forum was able to put a case forward for a range of new and progressive opportunities including one-to-one swimming lessons for children and adults; football coaching for SEND

team and one-to-one gym sessions for SEND teenagers, plus relaxation groups for adult carers.

#### Accessing funding

With a 'start-up' funding grant from Sport England and using the expertise of parents, the Leisure Centre was able to put together a package of specialist sport and leisure opportunities tailored to the needs of SEND children and young people in the City and neighbouring boroughs; something that was not available before, and suitable sport and leisure options are a reality for SEND families in the City for the first time.

Although the funding for the initial project has now come to an end, the project was so successful that the local authority has continued to fund the project, with the forum's involvement in ensuring parent voices as stakeholders and has reassured families that they intend to keep it in place well into the future.

#### Successfully helping disabled children access sport

A short film was recently made to highlight the success of the project. One parent reported that her eight-year-old son had been able to be part of a football team for the first time and this had been something that he had wanted to do for some time.



## SNAP PCF CENTRAL BEDFORDSHIRE

### Pathological Demand Avoidance (PDA) co-production

Many parents told the forum that they were struggling to get recognition and support for their children who had Pathological Demand Avoidance (PDA) due to different clinical viewpoints across health services. Whilst PDA is not included within the current diagnostic tools for autism (Diagnostic and Statistical Manual of Mental Disorders (DSM-V) and International Statistical Classification of Diseases and Related Health Problems 10 (ICD-10), the forum know that children need personalised support for their individual needs.

#### Co-producing training for parents and practitioners

The forum approached the PDA society and the local authority to see what could be done about this. Bespoke e-learning training was co-produced and delivered with parent carers whose children had PDA and this is now available for practitioners to access. Parents will soon be able to access it via the Local Offer without having to go through a school's portal.

## Increasing awareness of PDA

The forum felt that having a publicly available PDA position statement from the local authority would enable parent carers to signpost to health and other practitioners for further information and clarity. More LA funded training is planned so that it's available to all practitioners and parents who would benefit from it.

Having the PDA position statement and training in place has also increased the skills, knowledge and confidence of parent carers that took part in the work to sit on further strategic working groups, it has also raised the profile of SNAP PCF.

This work will increase awareness of PDA amongst families and practitioners and enable families to get the support that they need.

#### Resources

Read the [PDA position statement](#) and [forum document on PDA](#).

Additionally, the Forum Director won an award for championing SEND families called the [BAPS \(Bloody Awesome Parents\)](#) and had a blog written about their work.

The forum's website includes a [great film about the forum](#).

# Forum success stories



## PARENTSACTIVE (HAMMERSMITH AND FULHAM) CELEBRATE 20 YEARS OF PARENT PARTICIPATION

Parentsactive celebrated their 20th year with a booklet and online celebration event with volunteers, staff, and partners who have shown a steadfast commitment to improving the lives of families with children and young people with SEND in Hammersmith and Fulham.

### Embracing technology

The forum had adapted during the pandemic running many sessions virtually, and running face-to-face events when they could to reduce isolation, make connections, and increase parents' confidence. They set up WhatsApp groups including a peer support group, engaged dads on Zoom and increased their Twitter following to over 400 members.

### Training parents and practitioners

During 2020-21 Parentsactive ran training events and coffee mornings reaching 193

parents and 86 practitioners, resulting in 29 new members and 2 new committee members. Over 50% of new members were from diverse ethnic backgrounds. They ran training sessions on short breaks, benefits, Direct Payments, disabled children and the law, and transition. Parents fed into the development of the SENDIASS service which was recommissioned, with emphasis on health and social care advice and support.

They were involved in:

- *getting local authority funding for a dedicated worker at Parentsactive to support families through transition and after young people turn 25*
- *recommissioning the mediation service*
- *developing the Short Breaks Statement and eligibility criteria, as well as*
- *interviews and appointments of various key members of staff including the director of education and team leader for the EHC planning service.*

### Working with diverse groups

The forum ran vaccination awareness sessions which resulted in higher take up of vaccinations, particularly by Black and Asian parent carers. They worked closely with Mencap's advocacy service to signpost the most vulnerable families including refugees and those with English as a second language to support while ensuring their experiences were fed into the forum's work on service improvement.

Read about their work [Celebrating twenty years together.](#)



## HULL PARENT CARER FORUM BREAKFAST CLUB

Hull Parent Carer Forum meets fortnightly for Buffet Breakfast, a free, easy-to-access, safe, relaxed and informal session for parent carers, many with neurodiverse children and young people in mainstream schools. The breakfast club is conveniently after school drop off, and parents can turn up to have a free breakfast or cup of tea (key because of the financial strain on families).

This enables the forum to hear their issues and learn about good practice through their positive experiences. Parents also gain information and signposting to sources of support as well as peer support.

### Creating a community

The sharing of information has been vital to helping new families access services within the city, and beyond. Parents feel they belong to a community of people who 'get it'. The forum advertises widely through their social media networks, and membership has consistently grown, with the forum reaching parents who would not previously have got involved.

## Reasonable adjustments to allow parents to join in

Many parent carers of neurodiverse young people are also neurodiverse, and one of the keys to success has been that they understand the barriers to participation and have put in place reasonable adjustments to enable their full engagement. People who felt lost before the group began now feel like they are understanding services and are more confident in supporting and advocating for their child/young person.

### Engaging local practitioners

Local practitioners and service leads that families want to hear from come along to let parents know about their services and how to access them, answer questions, and to listen to the experiences of families on the ground. Feedback can be responded to quickly and parents feel more confident in being able to engage with services. The atmosphere is less formal and challenging and helps to build positive relationships and joint working in a positive and solution focused way. The forum now gets requests from providers who want to attend.

### Representing parents and finding solutions

Anonymous data and feedback is collated so the forum can evidence lived experience and reps use this to help them represent the wider voice at strategic meetings, sharing ideas and solutions as well as challenges and good practice, which helps to make a difference to families' lives.

# Contact's support for parent carer forums

Contact has been there from the beginning to support and empower Forums

## DELIVERING SUPPORT AND GRANTS TO FORUM

96.6% of forums told us they were 'very satisfied' or 'satisfied' with the support provided by their parent carer participation advisor. 100% of forums were happy with how Contact dealt with their enquiries about the grants process.

95.9% of forums were also happy with the communications from Contact, including our quarterly joint bulletin with the NNPCF.

We will take on board comments regarding improvements such as to the grant monitoring form, being able to apply for the DfE grant before 1st April, and about online learning.

*"As always the support from our advisor is extremely helpful, it is tailored to our needs and incredibly supportive."*

**Parent carer**

*"Very good. There is a lot of information and support available to us and everything works so well with Contact and NNPCF. We couldn't do without the support of our regional advisor."*

**Parent carer**

*"The service is always excellent, friendly and very helpful"*

**Parent carer**

*"As always we get good support from Contact, when we need support we get it quickly. Thank you"*

**Parent carer**

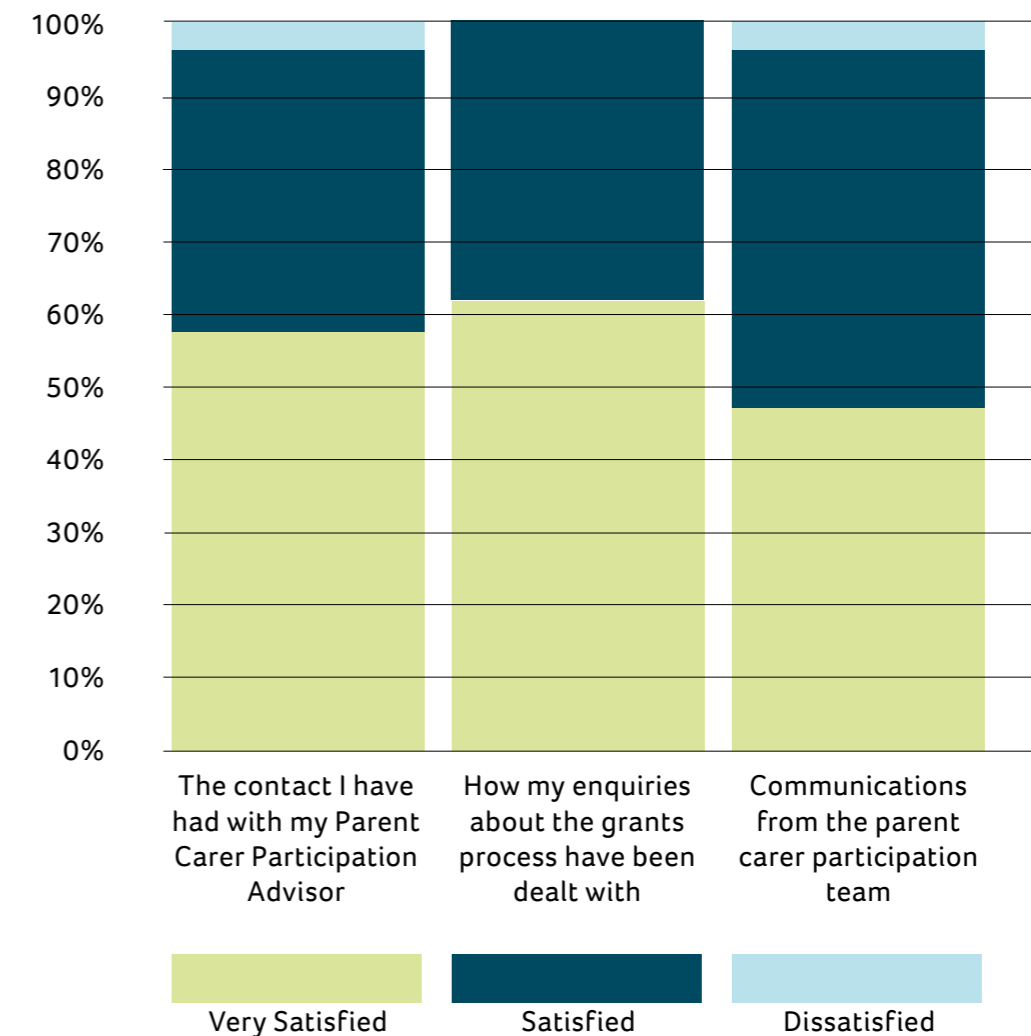
*"Everyone at Contact is very professional, approachable, and knowledgeable. It's good to know they are there for us whenever we need them."*

**Parent carer**

*"Our regional advisor has been excellent. She is very helpful and knowledgeable about forum business and the breadth of the issues we face and this has been a big help to us this year. In particular when we have had some challenges and questions and with our future plans, we have felt very supported and encouraged. This has certainly helped build our confidence and contributed to how we have been able to develop and grow and have such a successful year despite challenges."*

**Parent carer**

What forums thought of Contact's support in 2021/2022



## ONLINE LEARNING AND TRAINING

Contact provides learning and development opportunities to all Forums, equipping members with the skills they need to make a difference. In 2021/2022 we ran a total of 9 live online learning sessions on:

- **Grants**
- **Integrated Care Systems**
- **The Children's Social Care Review**
- **Legal Structures and Governance**
- **Digital Online Learning**
- **Safeguarding Children and Young People**
- **Positive Communications**
- **Co-producing the Local Offer**
- **Understanding Childhood Deafness**

We reached a total of 475 parent carers for live attendance, and a total number of 2,994 views. We also ran training courses on "Being a Parent Representative" and train the trainer to enable further opportunities and sustainability of the course, "Leading your Forum", and a pilot of "Communicating with Compassion".

Feedback on our training and online learning sessions was very positive and some comments from parent carer attendees are captured below:

*"Brilliant as always - I think they are a very valuable learning tool and being able to watch slides at a later date with wider team members helps to refresh some of the learning."*

*"Proud to be part of parent forums who together can make a difference"*

*"Easy to access, really good speakers. Thank you!"*

*"Value of joint working between Contact and NNPCF"*

*"More confidence to work alongside colleagues from CCG and NHS staff"*

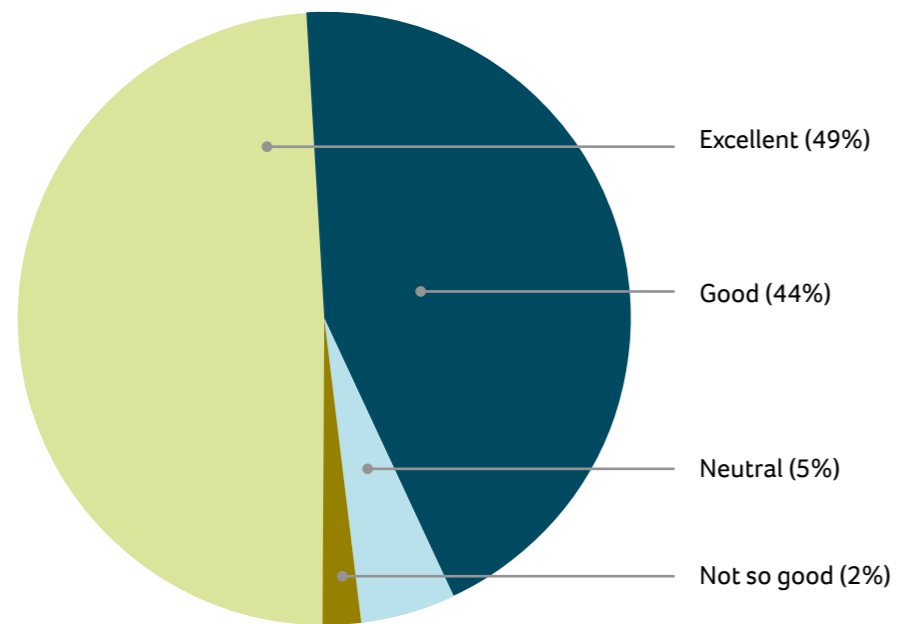
*"It was gratifying to learn that PCFs and parents individually are valued, and their experiences are considered important."*

*"The genuine understanding they...clearly have of the issues and pressures on forums is very comforting and supportive. All information was presented in a very calm and reasonable, common-sense manner that is much appreciated."*

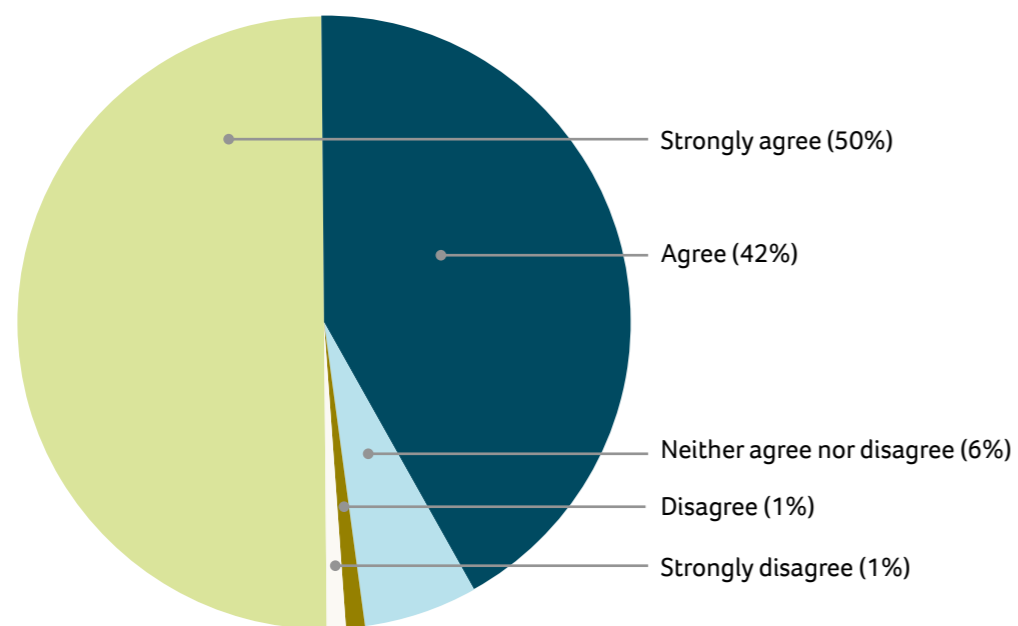
*"I will feedback to the rest of my forum members what I have learnt to enable us to be more positive about relationships with strategic partners."*



### Online learning session feedback



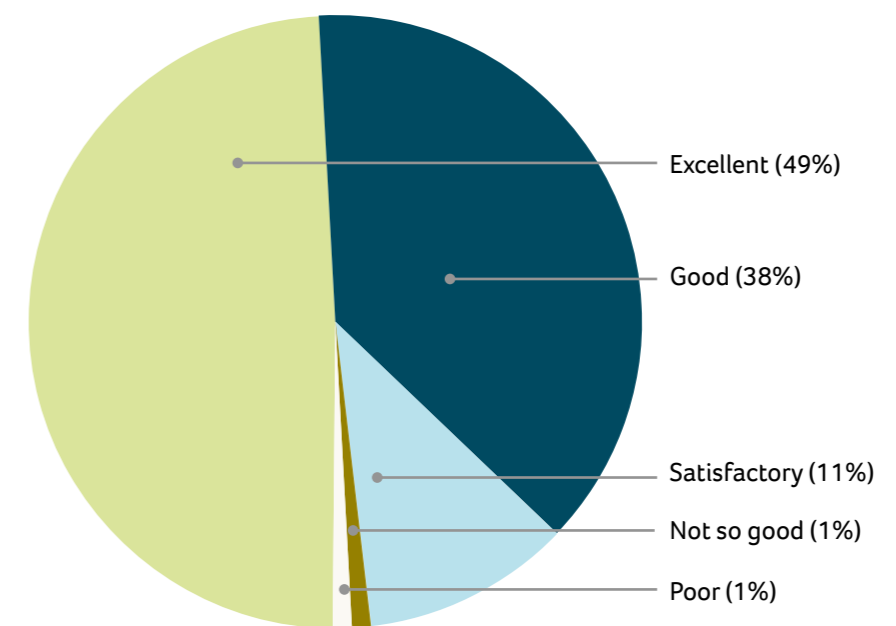
### I would recommend Contact training to others



### JOINT CONFERENCE

The annual joint conference from Contact and the NNPCF was held in two parts during 2021/2022 in late November/early December and March with a number of keynote speakers and a variety of workshops. There were 771 live attendees and 1,382 subsequent online views of the sessions making 2,153 views in total.

### 2021/2022 virtual conference – please rate the conference session you attended





# Funding the forums

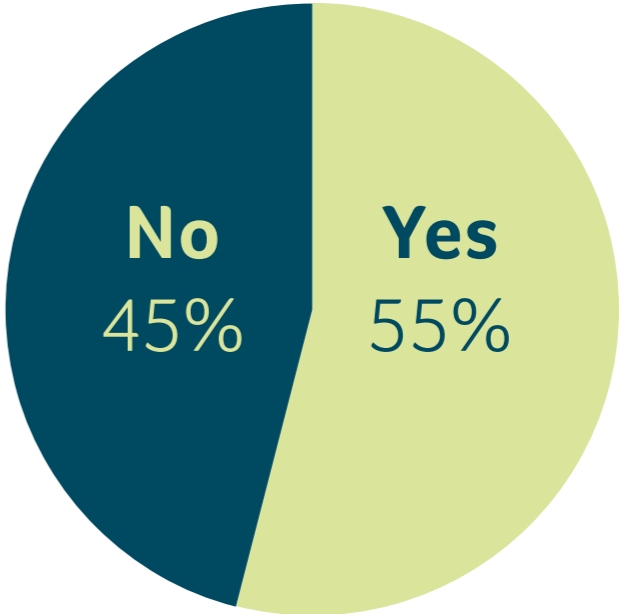
Funding levels of PCFs during 2021/2022 remained fairly static with 55% of PCFs attracting funding in addition to the DfE Participation grant (from 54% in 2020-21).

Many forums receive additional funding to top-up their DfE funding, to fund staff, to run specific projects, or support service level agreements. Whilst forums' core purpose is co-production with service providers, many have had to diversify to secure their future sustainability. Contact and the NNPCF continue to support the case for further central funding increases. During 2021/2022 53 priority grant applications were received from forums to enable them to carry out additional priority work, and we approved a total of £243,916, an average of £4,602 per forum that applied. Some of the priority applications were to fund regional

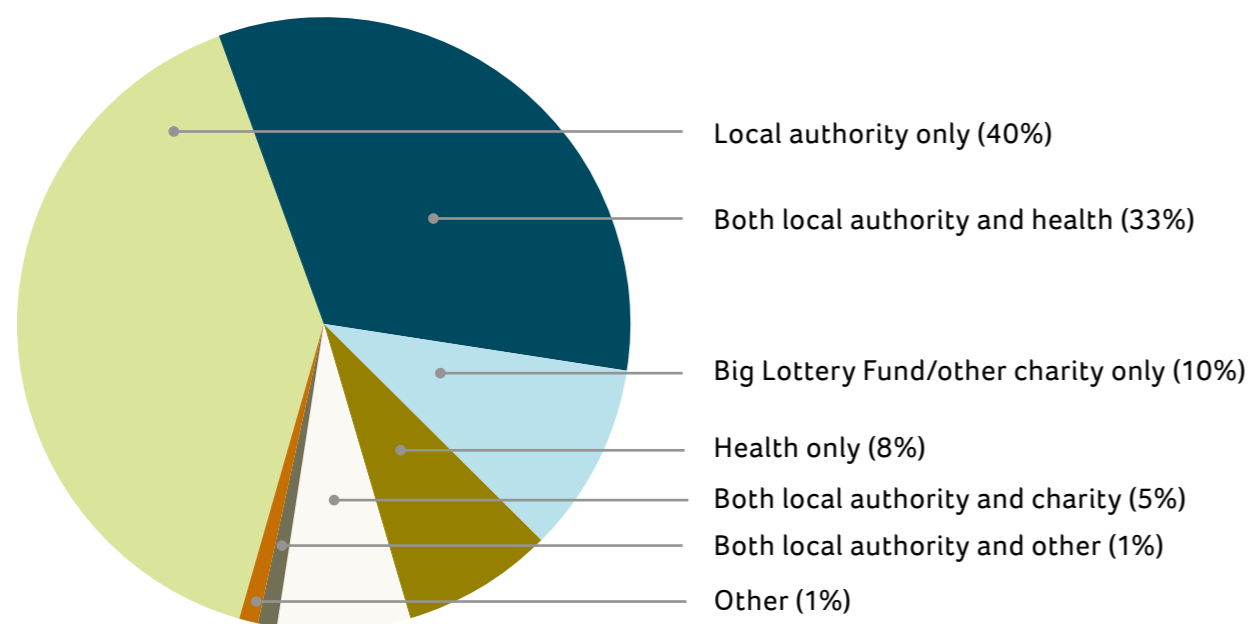
coordination and administration so that the regional networks could strengthen.

The funders themselves were largely the same with local authorities and health agencies making up the majority of the funding. The average amount of additional funding per PCF who responded was £26,101, a return to pre-pandemic levels of funding. Several PCFs received further funding from Pears/ Department for Digital, Culture, Media & Sport during 2021/2022. This enabled those forums to continue to offer some much-needed support to parent carers following the pandemic, in addition to their forum role.

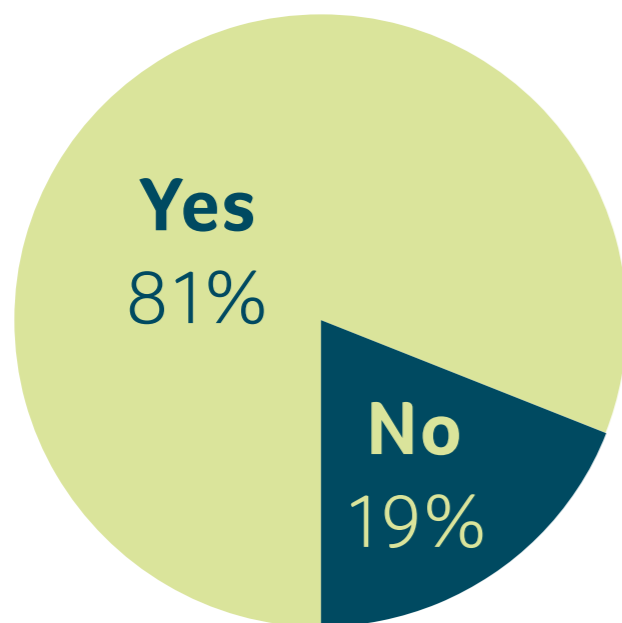
Did the forum receive funding to support parent carer participation in 2021/2022 (other than the DfE grant)?



Who funded the Parent Carer Forums in 2021/2022?



Does the Parent Carer Forum pay anyone to run or develop the forum?



There was a slight increase of 2% in the number of forums that employ staff to help to run the forum.

TELLING OUR STORIES

Stories about the impact of forums' work are vital to the continued funding of forums as they evidence the difference that forums make.

York Parent Carer Forum was able to welcome 100 parent carers and professionals to their annual conference discussing all things SEND. They said it was wonderful to be together after two years of lockdown. Feedback from families was fantastic and they are looking forward to next year's event.

Bury2gether were honoured with the Queen's Award for voluntary service, the highest award a voluntary group can receive in the United Kingdom. Their amazing group of volunteers give up their time to sit on strategic boards for SEND with the Local Authority and Health. They also run engagement and social events for families, all whilst caring for their own children with additional needs.



York annual conference



Bury Parent Carer Forum receiving the Queen's Award for Voluntary Service

# Looking forward

## Developing children and young people's participation and family support

Contact worked on the new tender for strategic participation and family support and we are delighted to have been successful in securing the three year contract along with our colleagues from the NNPCF, Council for Disabled Children (CDC) and KIDS who will support the development of children and young people's participation. The new contract will also include information, advice, and support which means that Contact's helpline and information offer and support to local SENDIASS services led by CDC falls under the same contract.

It sounds early but we will soon be thinking ahead to what support will be required in a future contract and so we will ask forums what they need going forward, and that forums share with us their success stories and the impact of their work to demonstrate to government the importance of continued for funding for PCFs.

We are looking forward to the next three years, but we understand that there will be challenges ahead.

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







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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