

# PARENT CARER PARTICIPATION 2017–2018

10 YEARS OF SUPPORTING PARENT CARERS' VOICES



Delivery partner of

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



Department  
for Education



## CONTENTS

A record year	4
Changing the lives of children with disabilities	6
Ten-year centre-spread pull-out: Looking back, looking forward	
The impact of parent carer forums 2017/18	12
How Contact Supports parent carer forums	14
Funding the forums	17

## 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.

### SUPPORTING PARENT CARER FORUMS

A key part of our work is supporting 152 local forums for parent carers of disabled children. The forums work with local authorities, health and education bodies and others to design and develop the best services and policies for families with disabled children. Collectively, parent carer forums are known as the National Network of Parent Carer Forums and use their shared voice to influence regional and national policy.

We’ve been the Department for Education’s delivery partner for these vital forums – which give parent carers a much-needed voice – since 2008, helping to set up and run them, and distributing grants to them.

This annual report explains how the forums made a difference to the lives of children and their families in 2017/18. The information comes from 147 grant monitoring forms the forums submitted to Contact, outlining their impact over the year.

For more detailed findings, visit our website: [www.contact.org.uk](http://www.contact.org.uk)



## A RECORD YEAR

---

The number of disabled children in the UK is growing, but cuts to public services and financial support for them and their families continue to bite.

Now more than ever, placing parent carers at the heart of decision-making is key to achieving the best possible value, and putting in place services and policies that really work for disabled children.

That's why Contact is so proud to continue to develop and support 152 parent carer forums across England, under contract from the Department for Education. The forums give almost 45,000 parent carers a voice and the opportunity to work with local education, health and other bodies on services and policies that can make a difference to their lives.

The forums work on a national scale too, coming together to form the National Network of Parent Carer Forums (NNPCF), which works to influence national policy at the highest levels.

### **A DECADE OF GIVING PARENT CARERS A VOICE**

For Contact, 2018 marks an incredible 10 years of supporting parent carer forums. During this time we've seen parent participation grow from a seed of an idea in 2008 to an influential movement today.

Still, there is more to do. In April 2018 we formed a consortium with the Council for Disabled Children, KIDS and the NNPCF to carry on supporting parents, carers, children and young people to shape the services they need. This was made possible by a new two-year contract with the Department for Education.

We'll also continue to build on our work with the 152 parent carer forums, which play such a vital role in decision-making in their local areas, giving them the support they need to thrive.

And we'll be working to improve the links between parent carer forums and children and young people's forums, so more children and young people can have an active voice in decision-making, alongside their families.

### **THANK YOU**

Thank you to every single one of the 44,641 parent carers who were actively involved in their local forums across England in 2017/18, and to all those who have volunteered their time over the last 10 years. You make an amazing difference.

We look forward to working with you to make sure parent participation continues to grow over the next 10 years!

**Gail Walshe,**  
Head of Parent Carer Participation, Contact



# LOOKING BACK, LOOKING FORWARD

2018 is the 10th anniversary of the Department for Education funding parents and carers' strategic participation in local decision-making. We look back over a momentous decade – and forward to our exciting future plans



It has been a key principle of government policy over the last decade that parents of children and young people should have an effective voice

in shaping policy and practice at local and national levels. The Department for Education has been pleased to support the development of the NNPCF through funding made available to Contact.

Parent carer forums in every area of England are having a significant impact and I have seen many examples of where they have made a huge difference. Personally, it has been a real privilege to work with the NNPCF. I have seen at first hand the positive impact that input from parents has made to policy development.

I am really grateful to all the parents and young people who have worked so hard, and overcome difficult challenges, to contribute to this success, and also to Contact for their support and leadership. Working together, you have achieved real and lasting change in culture and attitudes and I look forward to you continuing to have a strong voice in SEND policy at all levels.

**Ann Gross, Director,  
Department for Education**



## LOOKING FORWARD TO THE NEXT DECADE

Putting parents, carers and young people at the heart of decision making, whether individual or strategic, is central to everything Contact does. Our role in developing, supporting and nurturing parent carer forums and the NNPCF since 2008 has been a fantastic privilege but also just a natural part of everything we want to change and improve for families of disabled children.

We have seen tremendous change in some ways in the last 10 years. But in others we still have much to do, and Contact is absolutely committed to continuing this work.

The reforms of the 2014 Children and Families Act have created a structure that should enable parents, carers, children and young people to be in control of their lives. To ensure change happens, policy makers, decision makers and charities need to continue to be brave, supportive and empowering, hold their nerve and keep listening to what families tell us needs to change.

This will take time, effort and continued financial commitment but we know that where good co-production happens, attitudes change, relationships change and ultimately outcomes improve, not just for children and young people, but for the whole family.

**Gail Walshe and Amanda Batten, Contact**

## A WORD FROM THOSE WHO WERE THERE AT THE START



*"All the changes that have given a voice to parents have been hard fought. For many decades, service providers ignored the views and experiences of families with disabled children. This changed with the Every Disabled Child Matters campaign, when we brought together parents from different charities to demand inclusive services for disabled children and young people. This eventually led to the Aiming High for Disabled Children programme, significantly boosting services for disabled children and young people across England. With it finally came the recognition from policy makers that parents' participation was essential to designing services that met the needs of families. It was an exciting time. A time when the voice of parents was heard and acted upon."*

**Francine Bates, Chief Executive of Contact (2000-2007)**



*"I was involved in the early days of the Aiming High for Disabled Children (AHDC) programme back in 2008, and one of the core commitments was to set up a parent carer forum in every local authority. I remember the interviews we did for the contract, and being impressed with Contact and SERCO. They showed such insight into the need for proper investment and engagement with parents and families. The achievements made through AHDC and the parent carer forums remain one of the highlights of my career. I was amazed and delighted to hear that forum membership now stands at 93,412. I hope it goes from strength to strength and inspires governments of all sorts to keep the people at the centre of policy making."*

**Kate Sturdy, Long Term Strategy | Strategy, Policy and Analysis Group | Department for Work and Pensions**

**"A huge thank you to every one of the pioneering parent carers who've given their time, energy, passion and commitment during our first 10 years."**



**Contact organises series of Parliamentary Hearings** – parent carers tell MPs they need to be involved in shaping local services

---

**Every Disabled Child Matters** campaign, chaired by Contact, launches and lobbies for parent carer forums in every local authority

2006

2007

**First grants to set up parent carer forums** – £3,330 each to set up 151 forums secured from government by Contact

---

Only 465 parent carers nationwide known to be involved in planning local services at this point

2008

2009

**Grants increased to £10,000** for each area by government

2010

**First meeting of National Network of Parent Carer Forums (NNPCF)** brings forums together nationwide. Aims to influence national policy

2011

**Support and Aspiration green paper published** – forums work to embed parent carer forums in new legislation and guidance

2012

**Towards strategic co-production**  
Contact and NNPCF continue to influence green paper

2013

**National Network of Parent Carer Forums** formally constituted



**Children and Families Act 2014 published** – parent carer forums embedded in legislation

---

**Grants increased to £15,000** for each area by Department for Education

2014

**Forum membership hits 77,678** (up 16%)

2015

**Forums cited as key partners in joint Ofsted and CQC SEND inspections:** “gathering views of children and young people, and parents and carers, is crucial to these inspections.”

2016

**Largest ever conference of parent carer forums** – 245 attendees from 95 forums

2017

**More than 93,412 forum members!**

---

**Continued funding for strategic participation of parents, carers, children and young people** confirmed by Department for Education

---

**Contact, NNPCF, Council for Disabled Children and KIDS** form new consortium to take work forward

2018

**Aiming High for Disabled Children** launched in response to Every Disabled Child Matters campaign. Includes £5m from government to support development of parent carer forums



# CHANGING THE LIVES OF CHILDREN WITH DISABILITIES

This year parent carer forums supported more parent carers of disabled children than ever to influence the decisions that matter, and improve their families' lives

## THE DIFFERENCE THE FORUMS MAKE

From accessing the benefits they're entitled to, to getting the right healthcare, parents of disabled children often find themselves consumed by meeting their children's needs. Along the way, they become experts.

That's why it's vital they're involved in making decisions about services and policies that affect their families – locally and nationally.

The 152 parent carer forums we support all over England make this possible. The forums, made up of parent carers from all walks of life, work together with decision-makers to design, develop and improve services for disabled children in their local area.

They gather the views of local families and then work in partnership with local authorities, education settings, health providers and others to highlight where services, processes and commissioners are working well, or where improvements are needed. Contact plays a key role, helping parent carers to set up and run forums, as well as administering grants to them, on behalf of the Department for Education.

The forums' ultimate aim is to make sure their local services are the best they can be, fully meeting the needs of disabled children and their families.

### GREAT PROGRESS THIS YEAR

The forums now have

93,412

parent and carer members

△ 14% △  
up on last year

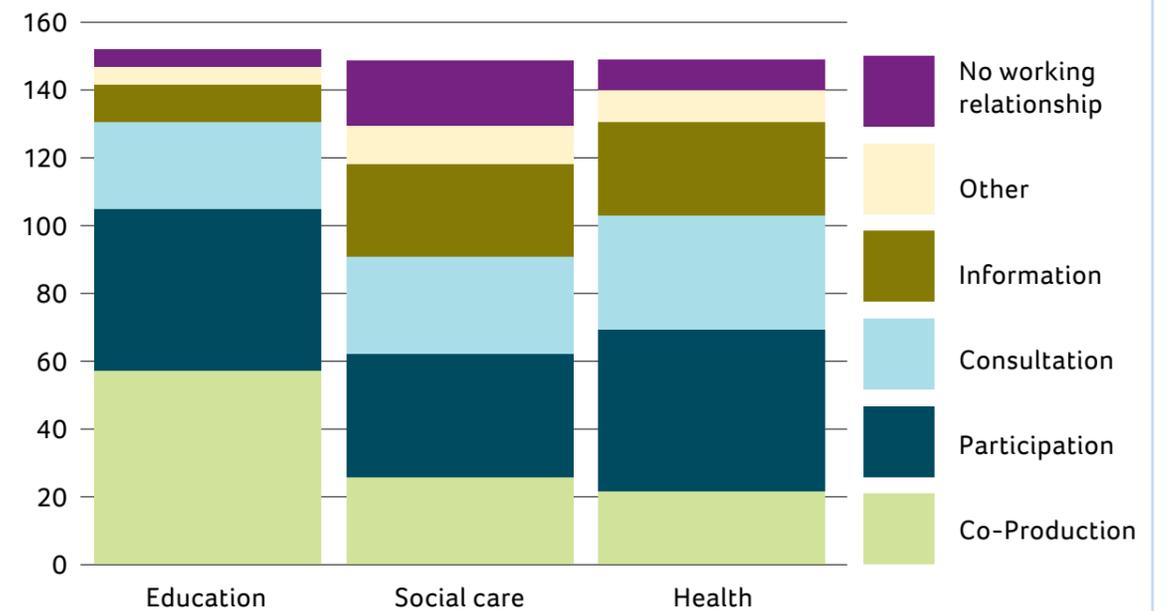
44,641

shared their vital knowledge and views of services to help forums influence local decision-makers

1,235

sat on their forum's management or steering group and were directly involved in running the forum or organising parent carer participation work

Levels of parent carer forum engagement with strategic partners



The forums also played an increasing role in co-production. Co-production is when forums play an integral and equal part in decision-making processes, and are fully engaged in shaping, developing, implementing and evaluating services and systems. In 2017/18, 56 forums reported they worked in co-production with their education partners, compared with 46 in 2016/17. This is an encouraging sign that the culture shift required by local areas by the Children and Families Act 2014 is continuing to embed with strategic education partners.

We also continue to see that parent carer forums are more likely to have co-productive relationships with strategic education partners than with their counterparts in health or social care.

102 forums were involved in preparations for OFSTED/Care Quality Commission inspections to assess their local area's effectiveness in identifying and meeting the needs of children and young people with special educational needs and/or disabilities in 2017/18, adding their vital voice to the process.

## REACHING SELDOM-HEARD GROUPS

Making sure forums have a diverse membership is vital to ensure they get a full picture of what life is like for all families with disabled children.

In 2017/18 forums worked hard on increasing their diversity, put plans in place in this area, and improved their data about seldom-heard groups. 52% of forums recorded the diversity of their membership.

To encourage these efforts, Contact asked for more detailed information this year than previously about how forums engage with seldom-heard families, including rural or geographically isolated families, low income families, and very new or young parent carers – as well as different ethnic groups. The results showed many forums were engaging with these groups, as shown in the figure opposite.

### HOW PORTSMOUTH PARENT VOICE REACHED OUT

“This year we’ve focused on finding out the views of three seldom-heard groups, and encouraging them to engage with the forum’s work: dads, ethnic minorities and home educators.

“It wasn’t easy to begin with. We tried running focus groups but they were poorly attended. We realised we had to go out to these groups, not expect them to come to us. So we did a lot of research and went along to relevant community groups.

“When it came to engaging with ethnic minorities, meeting Olufolake, a mother of disabled a child, was key. With our support, she set up the Moriah Support Group for parents who have children with special educational needs and/or disabilities from ethnic minorities. Olufolake has been key to helping us understand cultural differences and barriers to engagement, and the group is now really well supported, with membership growing.

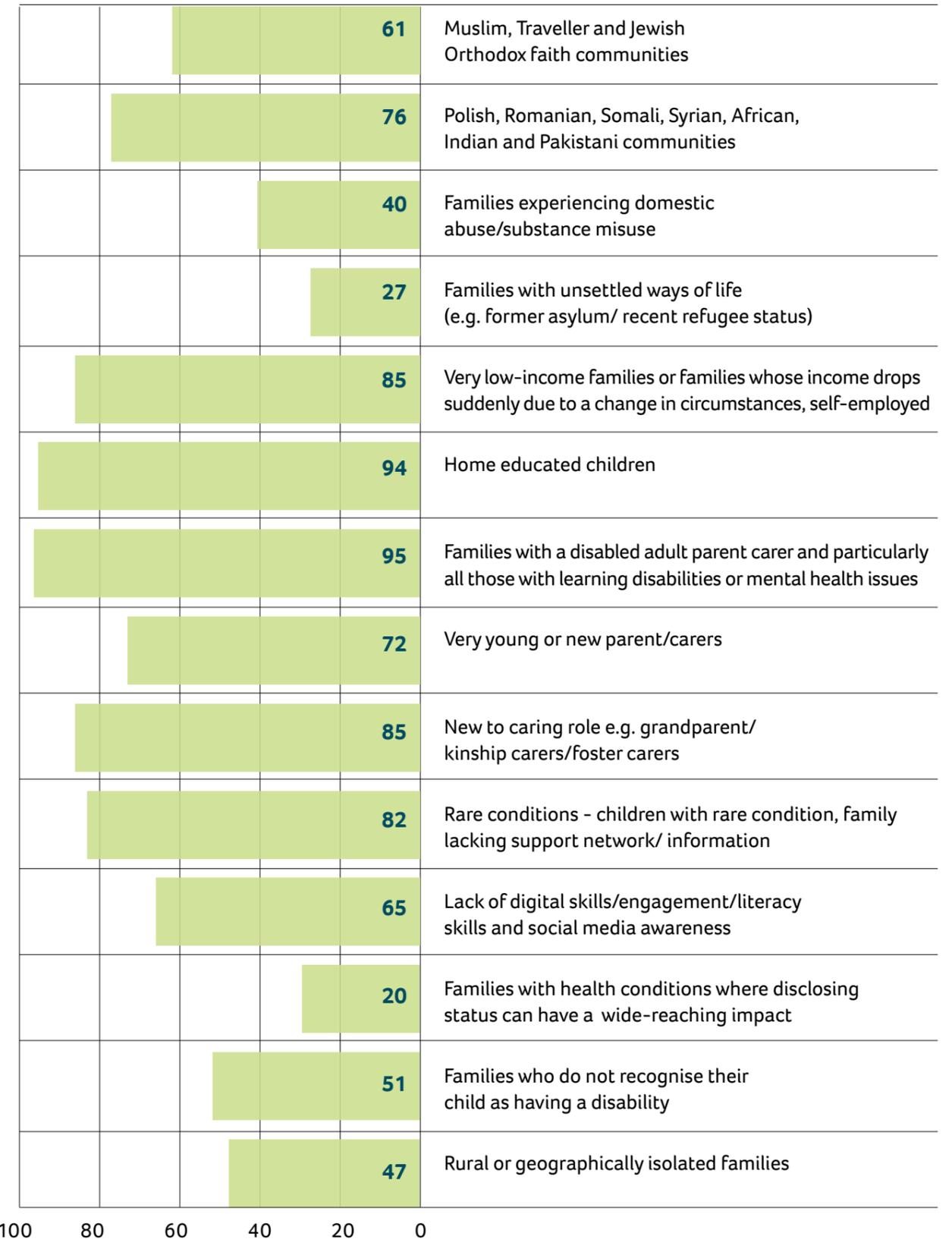
“Olufolake also recently attended the local autism strategy group. The original draft of the new strategy had nothing about engaging with ethnic minorities and seldom-heard groups, but that’s now included, thanks to Olufolake’s input.

We’re also working hard to encourage dads to get involved, and have done four workshops for home educators.”

If you’d like to find out more about this work and how Portsmouth are doing it please contact [ppvcoordinator@p-d-f.org.uk](mailto:ppvcoordinator@p-d-f.org.uk)



## Which of these groups has your forum successfully managed to engage with in 2017/18?



## INFLUENCING NATIONALLY

The National Network of Parent Carer Forums (NNPCF) is made up of representatives from the parent carer forums across England. It strives for the best policies for disabled children and their families at a national and regional level, working closely with the Department for Education, the Department of Health and other partner organisations. It also ensures that local parent carer forums are aware of national developments.

This year, the NNPCF steering group and national representatives from local forums contributed 642 days of their time to influence regionally and nationally. That's a 13% increase on 2016-17 – showing that both demand for the voice of parent carers, and the capacity to provide it is increasing.



## OUR IMPACT IN 2017/18

### DONCASTER PARENTS VOICE

“This year our forum was very involved in shaping our area’s new Independent Travel Training Programme, where children aged 16+ are taught how to travel independently by trained co-ordinators.

“We were actively involved in everything from planning the initiative, to putting together the contract requirements, setting the questions for prospective organisations who bid to deliver the programme, being part of the interview panel and rolling out the programme to young people and their families.

“A key element we managed to get included was taking a ‘whole family approach’ – making sure families were involved at every stage of the programme, liaising with co-ordinators to share how their child was doing and working together to get it right.”



### BOLTON PARENT CARER CONSORTIUM

“We were pleased in 2018 when our local authority invited us to take part in a detailed multi-agency review and consultation on provision for children with special educational needs and disabilities (SEND) in the area. The forum took part right from the very beginning.

“It resulted in a careful look at what children with SEND need in Bolton. As a result, the local authority has opened an additional new unit for children with autism attached to a primary school. They’re also consulting on new high quality ways to help children with social, emotional and mental health problems in the area.

“One element we particularly highlighted was that we weren’t against the local authority looking to reduce placements out of borough, something they were worried parents would be concerned about – as long as the right quality placement could be found in the local area that met children’s needs effectively.”

### LINCOLNSHIRE PARENT CARER FORUM

“Our biggest achievement over the last year has been our integral role in developing *Building Communities of Specialist Provision: A collaborative strategy for children and young people with special educational needs and disabilities in Lincolnshire*. The local authority invited Lincolnshire Parent Carer Forum to be involved from the start of the project. Without the forum the project board would not have heard the voice of parent carers in the way that it did during the development of the proposals.

“The forum represents families of children with a wide range of disabilities and additional needs and has been conscientious in ensuring that all types of disability have been considered. The forum has provided a great deal of challenge to the local authority and the school leaders and has been influential in helping to shape the proposal that was finally agreed to take to consultation. We have certainly not agreed with everything that has been considered and regularly provided constructive challenge to the local authority and health services in other areas of work too.”



### CAMDEN SPECIAL PARENTS FORUM

“We ran a Transport Focus Group in response to increased feedback from parents that there were problems with both the running of the service and the application process/eligibility. The meeting was an example of great collaboration between forum parents, schools and the local authority. We ran ‘problem solving booths’ to explore the problems and possible solutions.

“As a result the local authority will be producing guidance notes to accompany the transport policy. The guidance will be coproduced with parents from the forum. This has by no means solved the problems but has definitely raised awareness of the issues.”

# HOW CONTACT SUPPORTS PARENT CARER FORUMS

Contact is always on hand to support forums, and help them make the biggest impact possible

## GIVING FORUMS THE SUPPORT AND INFORMATION THEY NEED

To help forums have the best possible chance of improving life for families with disabled children, we offer them a wide range of support as part of our contract with the Department for Education.

Every forum has a named parent carer participation adviser, who they can contact any time for phone and email support about anything related to running their forum effectively.

In 2017/18, 137 forums said they were very satisfied or satisfied with the interactions they had with their adviser. 130 forums were similarly happy with how Contact dealt with their enquiries about the grants process.

We also continued to produce regular bulletins giving vital information and updates to forum members.

## VALUABLE WEBINARS

Contact also gives all forums access to learning and development opportunities, providing members with the skills they need to make a difference.

This year we delivered 11 webinars to 1,100 members, reaching forums across all regions. Members could watch live, or via YouTube later. Forums chose the topics, and the webinars were delivered by in-house experts, forums themselves or external partners. Topics included getting ready for the new data protection regulations; understanding and resolving conflict; decision-making for adults lacking capacity; and partnership working with support groups.

*"This was a very informative webinar. Gave me lots of food for thought. I will be watching it again for those fine points I missed while making notes and as a reminder of the information gained. Thanks."*

*"I felt empowered by the information and I look forward to receiving more information this way, as long as it is delivered to this high standard."*

*"I found it all really useful and it was in layman's terms. Thanks for making a difficult subject interesting."*

*"All the presenters came across as knowledgeable, warm and friendly."*



## PRAISE FOR CONTACT'S SUPPORT THIS YEAR

*"The support from our parent participation adviser and the Contact grants team has been timely, efficient and truly helpful. Any queries are answered fully, support offered readily and advice provided is based on the knowledge and experience of the adviser themselves."*

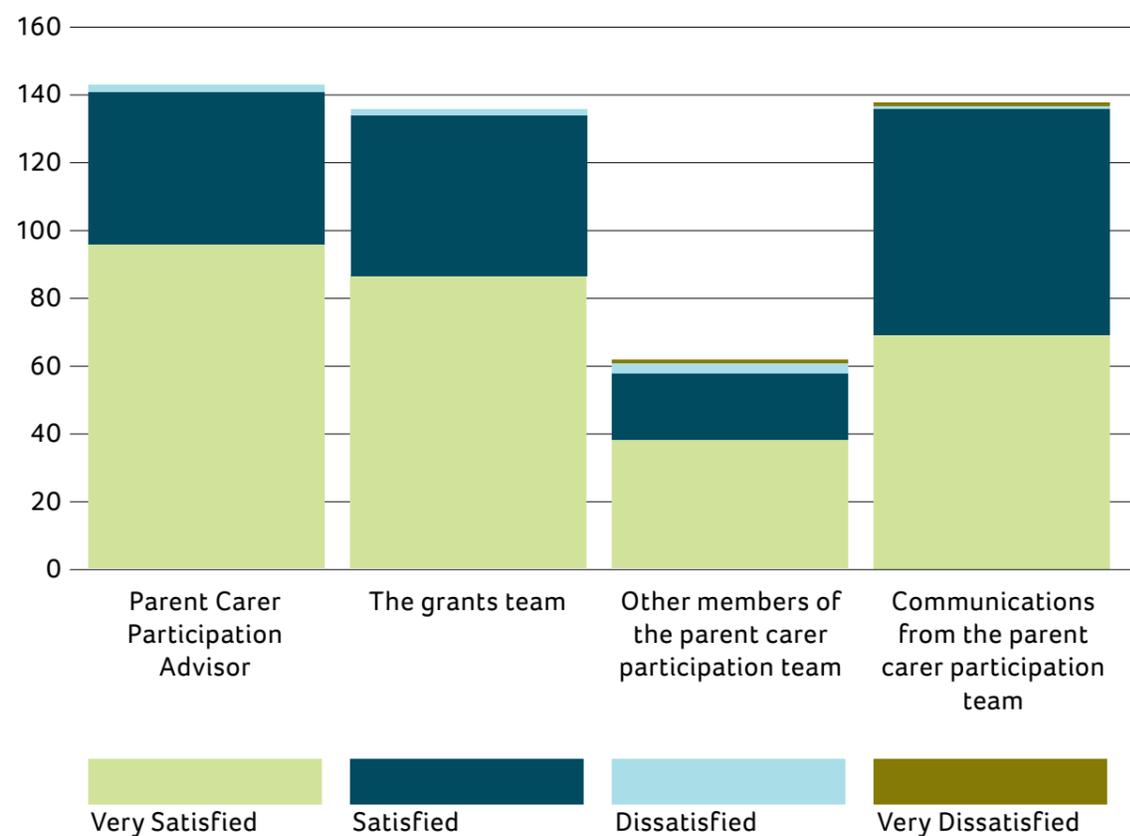
*"The information received in the regular joint bulletins is always really helpful. Contact and especially our parent participation adviser is always on hand when needed and always extremely helpful and supportive. Thank you."*

*"Our [Contact] adviser is really helpful, prompt and knowledgeable. She helps us think through issues in a constructive way. She is always available and makes time for us, which is much appreciated."*

*"I feel the service from Contact is fabulous, I feel very reassured knowing if we encounter any issues they are there to support us. They continue to do a wonderful job supporting and co-ordinating the parent forums. So a huge thank you from us for that!"*



What forums thought of Contact's support in 2017/18



## FUNDING THE FORUMS

Thanks to Contact and the National Network of Parent Carer Forums' (NNPCF) efforts, the forums have seen leaps in funding over the past 10 years. However, as demand for the forums increases, more is needed

Demand from authorities for parent and carer participation has grown, especially since the Children and Families Act was introduced in 2014. Education, health and other statutory and voluntary bodies are all seeing the huge benefits of involving parent carers in designing and delivering services and policies.

Membership of the forums has grown in line with this – but funding has stayed the same since 2014. Currently, the Department for Education (DfE) gives each parent carer forum a grant of up to £15,000 per year (which Contact administers) – up from £10,000 a year in 2009, and £3,330 in 2008, thanks to

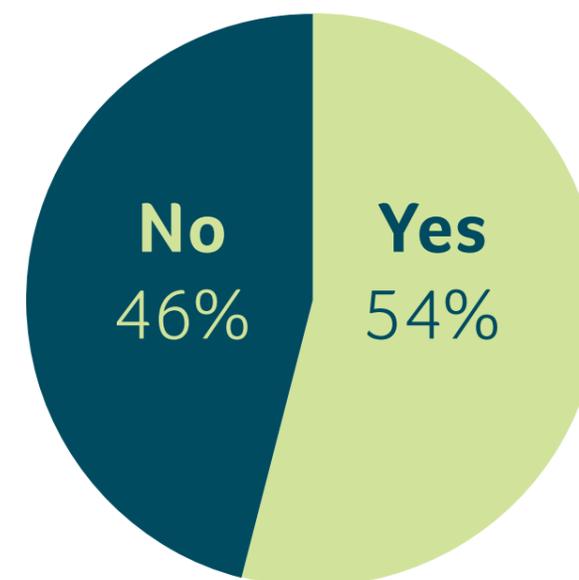
the impact of forums on service developments and Contact influencing for more investment.

70 of the 152 forums also received funding from other sources this year, totalling £1,558,027 – a slight rise on 2016-17. The average amount of funding this year per forum came to £19,475.

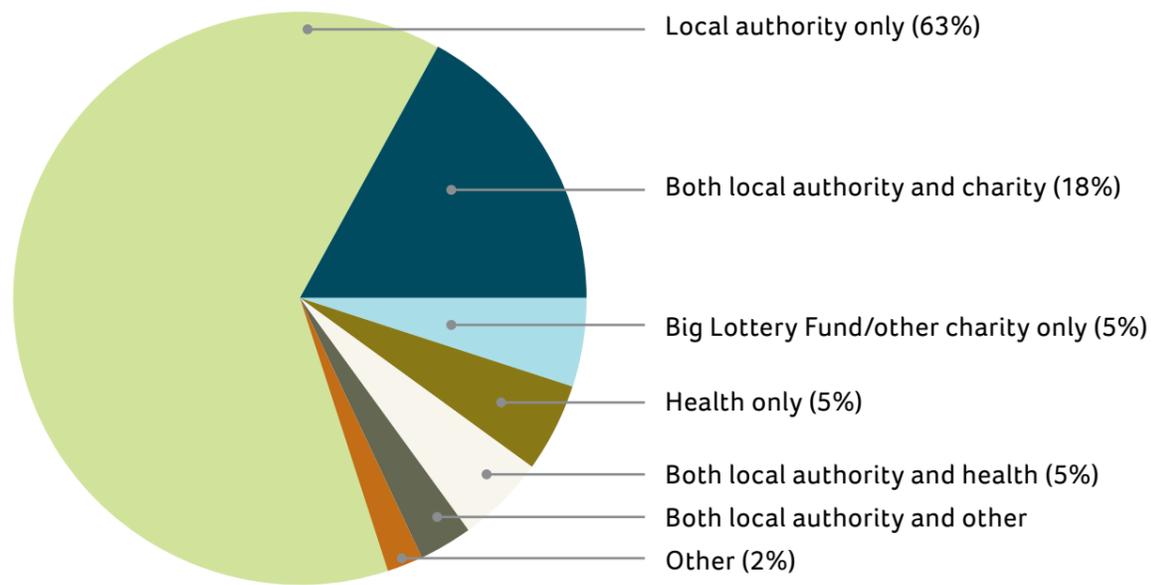
The DfE – and other funders – continuing to fund forums in this challenging economic climate demonstrates their huge value. And this funding is very welcome. But to improve even more lives by amplifying the voices of as many parent carers as possible, more investment is vital.

Contact will continue to work hard to get more funders on board next year.

### DID THE FORUM RECEIVE FUNDING TO SUPPORT PARENT CARER PARTICIPATION IN 2017/18 (OTHER THAN THE DfE GRANT)?



## SOURCES OF ADDITIONAL FUNDING



*“Something quite magical happens when people sit down together, talk, listen and work things out. Barriers come down, fear and ignorance flies out the window, and respect, understanding and goodwill takes its place.”*

Parent carer, Sutton Parents' Forum





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



020 7608 8786



[fundraising@contact.org.uk](mailto:fundraising@contact.org.uk)



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



[twitter.com/contactfamilies](https://twitter.com/contactfamilies)



[facebook.com/contactfamilies](https://facebook.com/contactfamilies)



[youtube.com/contactfamilies](https://youtube.com/contactfamilies)

Contact Head Office  
209–211 City Road  
London EC1V 1JN