

PARENT CARER PARTICIPATION 2018 – 2019

THE NEXT DECADE OF SUPPORTING PARENT CARERS' VOICES





ABOUT CONTACT, THE CHARITY FOR FAMILIES WITH DISABLED CHILDREN

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Delivery partner of



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 Contact’s work is supporting and developing the 151 local Parent Carer Forums across England. Forums work with local authorities, health and other local partners to influence, design and develop the best possible services for children and young people with special educational needs and disabilities (SEND).

Contact has been the Department for Education’s (DfE) delivery partner, supporting and developing Parent Carer Forums since 2008. We help forums to set up and operate, as well as administering each forum’s annual £15,000 DfE grant.

This annual report uses grant monitoring data to highlight the difference that Parent Carer Forums made to the lives of children and young people with SEND and their families in 2018/19.

For more detailed information and resources to support Parent Carer Forums, visit our website: www.contact.org.uk



A WORD OF THANKS



Thank you to each and every one of those parent carers whose opinions and views have helped to make improvements to services across local areas in England. Your efforts are being recognised. The difference you are making is immeasurable. We are also beginning to see strides forward in children and young people's participation.

Parent carers and children and young people themselves are the experts in determining what they need, because they have the lived experience of the impact of both successful, and poor provision. It's these experiences that help to shape improvements and make positive changes. This reports celebrates how parent carers can work together with services to help them to find more suitable and workable solutions that also enable them to target their resources where they are needed most.

Carolyn Deveney, Head of Parent Carer Participation, Contact



That Parent Carer Forums are operating well in these challenging times is testament to the hard work and diligence from their core groups and

wider memberships. We know that running a Forum can be incredibly demanding, especially as parent carer volunteers also have caring responsibilities.

Contact is proud to support Parent Carer Forums and the National Network of Parent Carer Forums and we are committed to listening to what they need to make them strong and sustainable for whatever the future brings.

Gail Walshe, Director of Participation and Regional Development, Contact

“Thank you to each and every one of those parent carers whose opinions and views have helped to make improvements to services. Your efforts are being recognised. The difference you are making is immeasurable.”



THE IMPACT OF PARENT CARER FORUMS

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.

THE DIFFERENCE THE FORUMS MAKE

Parent representatives on boards and work streams input feedback, views and evidence from their members at the right time to providers and commissioners to ensure that their voices are heard.

By working alongside services, Parent Carer Forums help them to find more suitable and workable solutions that also enable services to target their resources where they are needed most.

Parent Carer Forums have also been able to reverse some unpopular decisions to change, or make cuts to services that were working well.

Parent Carer Forums had to contend with the introduction of the new GDPR legislation in May 2018 which resulted in the deletion of many parent carers from forums' databases. We predicted a significant drop in wider forum membership as a result; in reality, the drop has not been as sharp as anticipated and we have seen a significant increase in their reach via social media channels.

THIS YEAR

The forums have
88,293
parent and carer members

52,180
shared their vital knowledge and views of services

△ **17%** △
up on last year

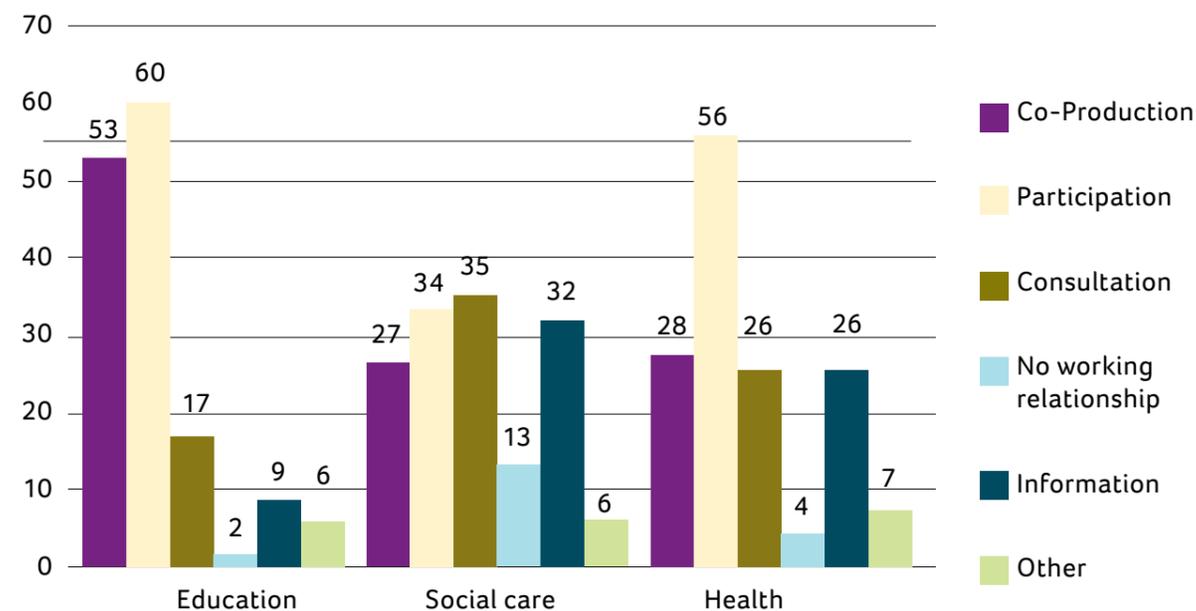
1,274
sat on their forum's management or steering group

177,654
parent carers reached online

△ **105%** △
up on last year

STRATEGIC ENGAGEMENT OF PARENT CARER FORUMS

Levels of parent carer forum engagement with strategic partners



A WORD ABOUT CO-PRODUCTION

Co-production is an important principle in parent carer participation.

Co-production happens when all partners play an integral and equal part in the decision-making process and are fully engaged in shaping, developing, implementing and evaluating services and systems.

The gold standard

Evidence shows that co-productive partnerships make the best use of people's time and money, whilst also improving outcomes for disabled children. It is the gold standard of working. However, it means that strategic partners must make a commitment

to engage with Parent Carer Forums to shape and develop their services.

This year, Parent Carer Forums continue to play an active role in local, regional and national co-production.

78 forums were involved in their local area's preparations for OFSTED/Care Quality Commission inspections during 2018-19, adding their experience and knowledge to the process.

Co-production in education

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

REACHING SELDOM-HEARD GROUPS

Forums having a diverse membership is vital to ensure they get a full picture of what life is like for all families with disabled children and young people.

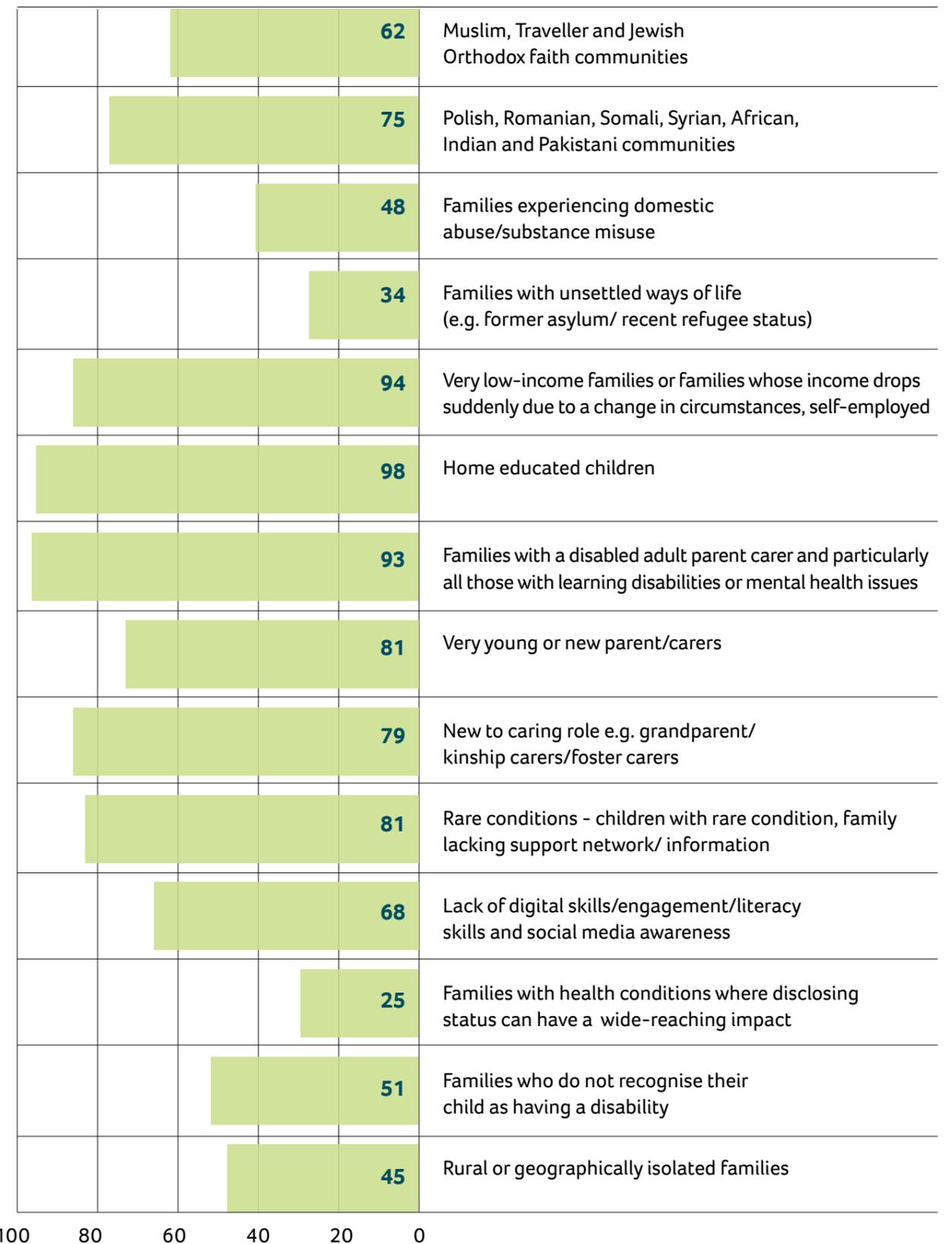
In 2018-19 Forums continued to work on increasing their overall diversity. Many put plans in place in this area and managed to improve their data collection relating to seldom-heard groups.

Half of forums recorded the diversity of their membership. The majority of forums (130) are engaging with many of their area's seldom heard groups, and continue to make progress, as shown in the figure on page 9.

Engaging communities

This year, to support forums to have more confidence to make connections with seldom heard communities, Contact worked with Include Me TOO and several Forums to map their local area and population and identify community groups they could link with. From this work a toolkit was developed that shows Forums where to find the information they need about their community, and then how to approach them, with a view to engaging them in the Forum's work. The toolkit will be finalised during 2019-20 and will be made available to all forums.

Which of these groups has your forum successfully managed to engage with in 2018/19?



INFLUENCING NATIONALLY

This year, Contact has continued to support and empower the National Network of Parent Carer Forums (NNPCF) which is the umbrella organisation for all the Parent Carer Forums in England.

The NNPCF strives for the best policies for children and young people with SEND and their families across local areas, regions, and nationally. 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 – better services and improved outcomes for children and young people with SEND, and their families. The NNPCF also ensures that local Parent Carer Forums are aware of national developments, consultations and opportunities to shape policy.

During 2018-19 the NNPCF steering group members, who are also members of local forums, contributed 693.5 days of their time influencing regionally and nationally on behalf of their members. This was 38.7% above their annual target.

Similarly, the NNPCF national representatives contributed 138 days of their time, also 38% above their target. This demonstrates the continued demand for the voice of parent carers in strategic decision-making arenas.





HULL – SYNERGY

“In Hull, we wanted to find out whether working with children and young people could help them to engage effectively in the decisions that affect them. With synergy in mind, KIDS’ young people’s group in Hull, Loud Mouths, set up a working group that also includes representatives from Hull Parents Forum. We discussed how working together could have benefits and improve the way in which young disabled people’s voices are expressed and received in the strategic decision making process.

To share our joint learning with others, we co-produced an engaging ‘Snakes and Ladders’ game that provides participants with questions to ponder as they move across the board – advancing via the ladders, or descending via slippery snakes, that represent the ups and downs that we might experience on our participation and co-production journeys. We’ll produce a workbook to accompany the resource once fully developed to help others to use the game.”

Laura Dixon, KIDS, and Laura Jones, Hull Parents Forum

SOMERSET – INCREASING MEMBERSHIP

“When our forum reformed in 2015, membership records were in a mess. We appeared to have around 250 members but it was unclear who were full members and who were in touch through social media only. We decided to address this by acknowledging that although some parent carers were happy to attend events where they could share their views, not all wanted to become members, especially if they were already part of other local groups.

We worked with Contact to visit local support groups to talk about our Forum – you can read about how we did this on the our website. As a result, we now hold regular meetings with condition-specific groups across Somerset, and offer parent carers different ways to engage with us like Facetime, Skype, conference calls and individual phone calls. The hard work has paid off and we now have over 1,800 members, with an online reach of up to 40,000 hits per month. This gives us access to the views and wider intelligence of many more families and a membership that is much more inclusive and representative of our area.

Tina Emery, Vice-Chair of Directors, Somerset Parent Carer Forum



EAST RIDING OF YORKSHIRE – INCLUDING HEALTH INFORMATION IN EHC PLANS

“Parents told us that there was little or no health input into Education, Health and Care Plans – or that health information was incorrectly being added to the education section of the plan. This was having a detrimental effect on families: children weren’t getting the right support for their health needs. We raised this at the monthly strategic SEND feedback meeting – and they listened. Working in partnership with the Designated Clinical Officer, we produced a template health questionnaire for parent carers, which was accepted by commissioners. The health questionnaire is now part of the process for an assessment for an Education, Health and Care plan (EHCP). Parent carers can complete the questionnaire and the information, such as the names of involved practitioners, acts as a checklist to ensure that health practitioners are involved in providing health reports which contribute to the EHCP, which avoids health needs being overlooked. The outcome of the collaborative work is that children and young people have their health needs addressed appropriately in their EHCP.”

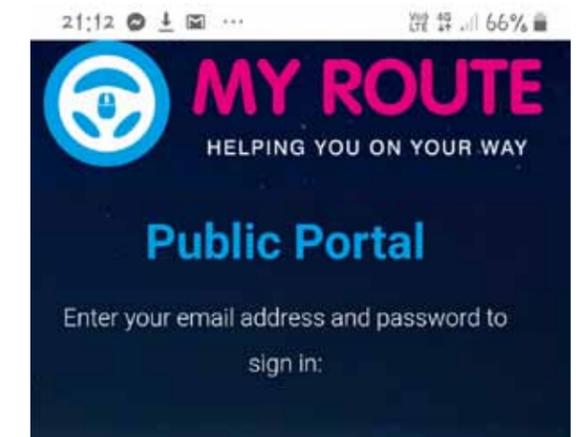
Shirley Pethick, Co-chair, East Yorkshire Parent Carer Forum

KNOWSLEY – MAKING SCHOOL TRANSPORT BETTER

“In Knowsley we worked with the local authority, contractors and schools to co-produce ‘My Route’, an online, mobile-friendly portal that helps parents apply for school transport. Before, they had to fill in a complicated, jargon-filled postal application form for their child’s school transport. Parents can also call the local authority’s ‘digital champions’ for extra help attaching evidence to support their application. My Route is now live and has cut down the time for transport to be awarded from weeks to minutes. Communication between the council and parents has improved, the council is reporting fewer transport refusals, and the forum is receiving fewer complaints about transport.

“The local authority described our input as invaluable, making their application process clearer and easier for parents to understand. We’ll continue to work with the council on further improvements with the longer-term plan to make it accessible to all, with easy to understand layouts and processes.”

Debbie Smith, Knowsley Parent Carer Voice



HOW CONTACT SUPPORTS PARENT CARER FORUMS

Contact is here to support forums with their day to day running, and empower them to increase their impact. This includes providing forums with the resources they need to do this.

GIVING FORUMS THE SUPPORT AND INFORMATION THEY NEED

Contact offers a wide range of resources and support as part of our consortium contract with the Council for Disabled Children, KIDS and the NNPCF supporting the Strategic Participation of parent carers and children and young people with the Department for Education.

In addition, each forum has a dedicated member of Contact staff – a parent carer participation advisor – who can be contacted for phone and email support about running an effective forum. Contact’s website is full of useful resources for forums at each stage of development.

Of 141 forums who responded to our survey, 98.6% of forums were either very satisfied or satisfied with Contact’s advisor support. 99.3% of forums were also happy with Contact’s response to their enquiries about the grants process.

Contact delivered 10 webinars in partnership with forums, external partners and experts during the year on the topics that forums identified such as support around grant monitoring and applications; understanding legal structures; engaging with health; SEN transport; staffing and workforce development; HR; local area inspections; fundraising, and an Information, Advice and Support Service (IASS) update. These webinars reached more than 600 forum members across all regions. Forum members told us:

“You made it as interesting as possible - the examples were helpful and answers to questions open and transparent and helpful - good job folks”

“Great webinar. Lynn is very knowledgeable - I now have an ‘action list’ to share with my parent reps. Thank you :)”

“Really easy to listen to and understand, a really useful and informative presentation and lots of great ideas about where to find out more.”



PRAISE FOR CONTACT’S SUPPORT THIS YEAR

“We have felt very supported by Contact over the last year and look forward to working closely with them in the future.”

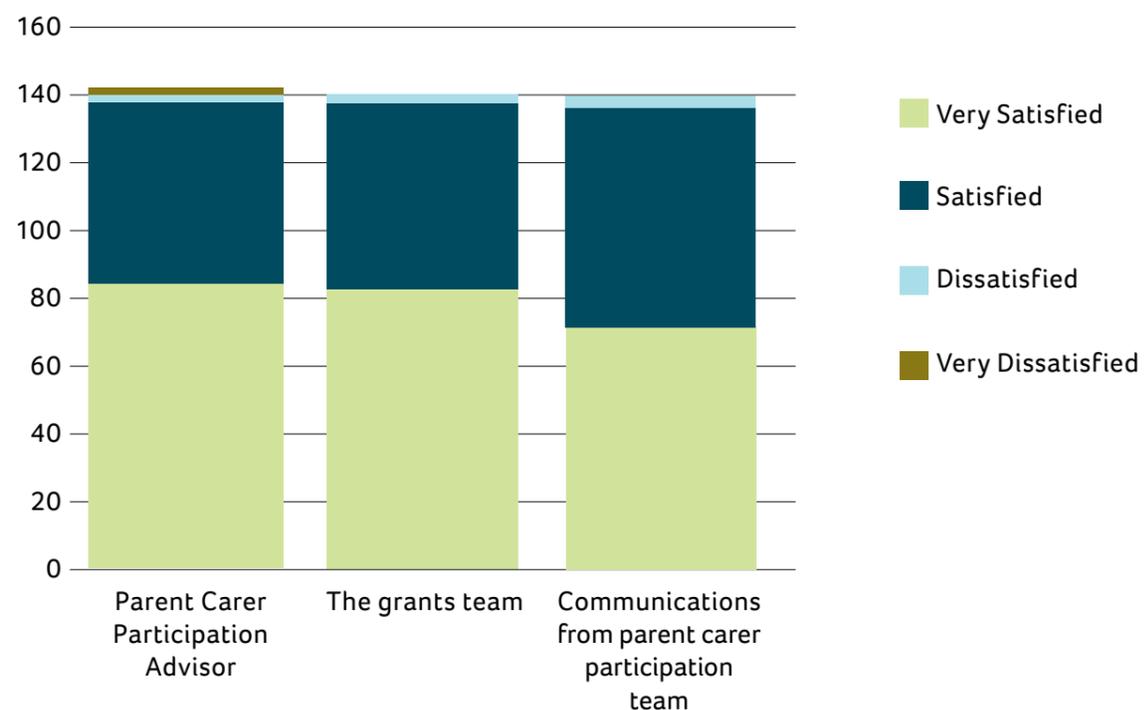
“The service and support we receive from Contact is exceptional. They are always there at the end of the telephone (or in person) to offer knowledge, advice and support whenever it is needed and we are very thankful for that.”

“We highly value the support of our Contact advisor and the grants team. They are always on hand and are approachable, knowledgeable and very encouraging”

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



What forums thought of Contact's support in 2018/19



FUNDING THE FORUMS

Due to the high profile and impact of Parent Carer Forums and their work with services, the demands on their time has increased year on year. However, if forums are to continue to be sustainable, and able to remunerate representatives for their time, more investment in forums is needed.

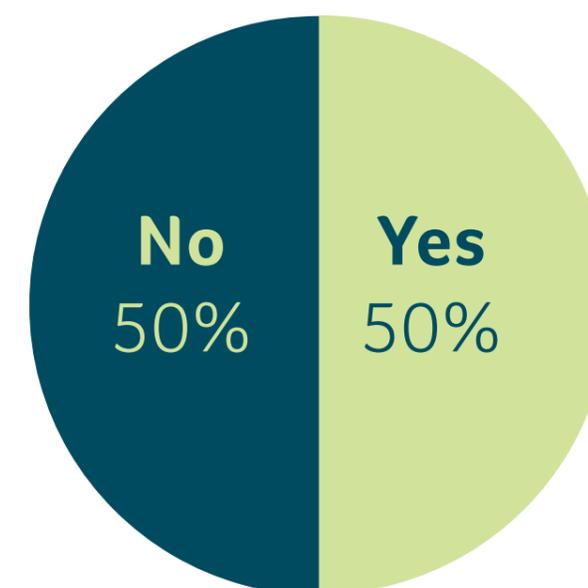
Following the implementation of the SEND reforms in 2014, the workload of forums has increased. Forums are invited to attend more meetings including those to plan their local area inspections. Their presence is also required during and post-inspection. Forums struggle with capacity and are largely reliant upon volunteers. Some Forums remunerate parent reps for their time, in part due to additional funding from their local authority, health, or from other grants. That Forums continue to receive core funding at a time of political uncertainty is testament to their impact and ongoing success.

However, Forums have not seen an increase to their core DfE funding of £15,000 since 2014 – despite their growing membership and

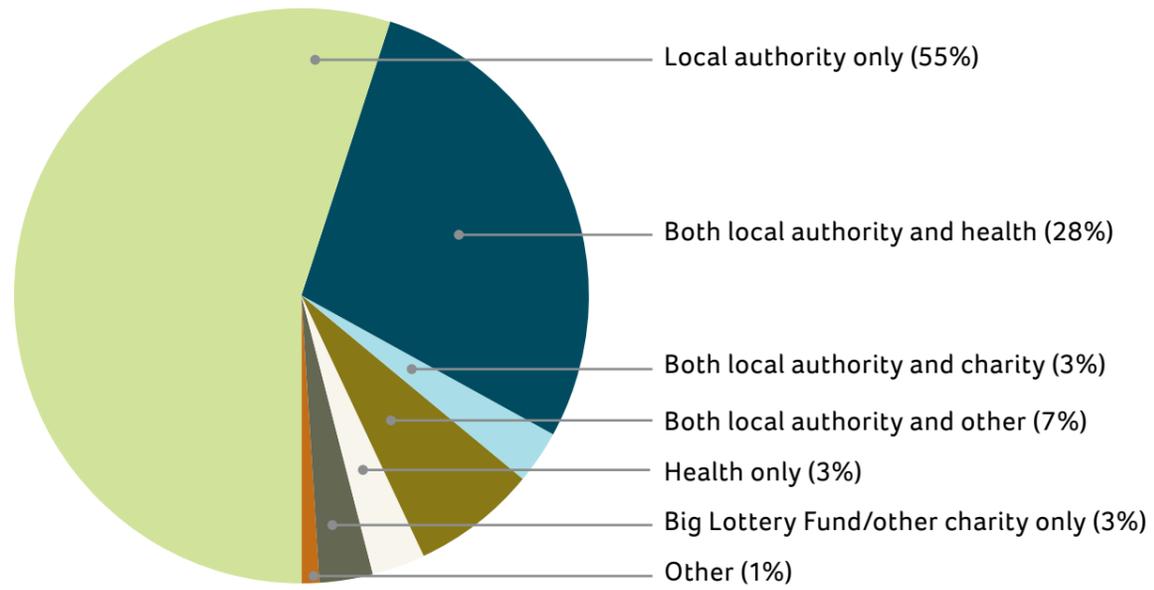
more active members and reps taking part in strategic boards. Both Contact and the NNPCF continue to make representations to the DfE, the Department of Health and Social Care, and NHS England to seek further funding to support the work of forums, particularly in the health arena as there is much future work anticipated for forums and the NNPCF on the NHS Long-term Plan.

74 of the 150 Forums in 2018-19 received funding from other sources totalling £1,606,496 – a slight rise from £1,558,027 in 2017-18. The average amount of additional funding during 2018-19 per forum was £21,709.40, an increase from the 2017-18 average of £19,475.

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



SOURCES OF ADDITIONAL FUNDING



“We’ve seen outcomes improving, we’ve seen relationships improving, and we can demonstrate that we have made a difference to children and young people today.”

Head of SEND, speaking about co-production.





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

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



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