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National Network of Parent Carer Forums  
'Our Strength is our Shared Experience'  
[www.nnpkf.org.uk](http://www.nnpkf.org.uk)

# contact

For families  
with disabled children

## Welcome to the first joint newsletter of 2019

Forum work resumed at full-tilt in 2019 with forums organising and running events before the end of the current financial year, regional events, and national workstreams and meetings.

Thanks to you all for your dedication and ongoing work in ensuring that parent carers' voices continue to be heard, and for the difference that you make in your local areas for children and young people with SEN and disabilities.



## Discretionary Grant update

We were able to award all of the Discretionary Grants submitted and in most cases, we were able to give the full award to forums. We'll be rethinking the process next year to try to ensure that the DG process is more equitable.

## Important information for forums with new bank accounts

Due diligence checks by the Department for Education on new bank accounts may **delay receipt of parent carer participation grant** by up to six weeks - if your forum has changed its bank account, is a new forum, or will be changing bank account before applying for the 2019-20 grant, the forum will need to **complete a DfE proforma** notifying them of these new account details. **If done now, it will minimise any delay** in receiving your grant payment as checks may be complete by the time your application is submitted. For further information and to request the proforma, please contact the grants team - [pcfgrants@contact.org.uk](mailto:pcfgrants@contact.org.uk).

## 2019-20 Parent Carer Participation Grant

Links to the application form for the 2019-20 grant, and monitoring form for the 2018-19 grant will be available on [our grants page](#) on or before 1st April.

## Quality Indicators for Co-production and Inclusive Practice

Contact, Genuine Partnerships, the NNPCF, NDTi, NHSE, CDC, KIDS, Mott MacDonald and Local Authorities have been working together to produce a framework '[the Quality Indicators of Co-production and Inclusive Practice](#)'. It is based on the cornerstones of co-production which underpin successful partnership working and ensure a shared

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understanding of what it should feel like if co-production is working well. The framework can be used to help identify good practice in co-production, and also any areas that need developing.

## Videos and presentations from the 2018 National Event

Videos from the November National Event are available on the [Resources from the National Event 2018](#) page. See the [highlights film](#), video about the [difference parent carer forums](#) have made in 10 years and [blog from one of the attendees](#).

There's also Nadhim Zahawi's [key note speech](#) and Amanda Batten, Contact CEO talking about [ten years of parent carer forums](#). A further film [on NHS England - Where we are now and next steps](#) will be available soon.

## Contact's 40th Anniversary Awards



To mark our 40th anniversary, Contact is running the 'Together at 40' Awards which recognise children, family members, groups and people who have made a difference to children and families. Almost 500 nominations were received across the categories which included the **Parent Power Award** and **Excellence in Parent Carer Participation**. Shortlisting will now begin! Finalists will be announced in April or May and winners will be announced at an Awards Ceremony in London later this year.



## Ambitious About Autism - Right from the Start project

Ambitious about Autism is starting a new project called Right from the Start, exploring access to support in the early years, including early intervention, for families with young autistic children. Over the next year they will be gathering evidence to inform a parent-friendly, accessible information pack to help parents feel better informed, and supported in a timely way.

If you are a parent/carer of a child aged 0-6 years old with a diagnosis or suspected diagnosis of autism, please share your experiences by completing our survey.

The survey is available in two versions:

1. [Online version](#): this can be completed and submitted online.
2. [Paper version](#): this can be requested online via the form or by sending your details and address to [familyresearch@warwick.ac.uk](mailto:familyresearch@warwick.ac.uk) or call the research team on 024 7657 5866.

## Greenwich - embracing diversity film

Greenwich's [Embracing Diversity film](#) was produced to communicate, parent to parent, a message of hope and positivity about disability. It is part of a wider Greenwich Parent Voice project aiming to challenge and counter the stigma of disability in BAME communities. The forum say that these beliefs are rooted in tribal African culture. Because of the perceived 'curse' of disability parents are in denial, isolated and often refuse to accept support at school. The forum asked parents who they know to talk about their positive feelings and experiences. Within a few days of being up on YouTube it had many hundreds of views. The forum hopes that it can help to spread a positive message wherever this issue exists and they would love other forums to share it with their communities.

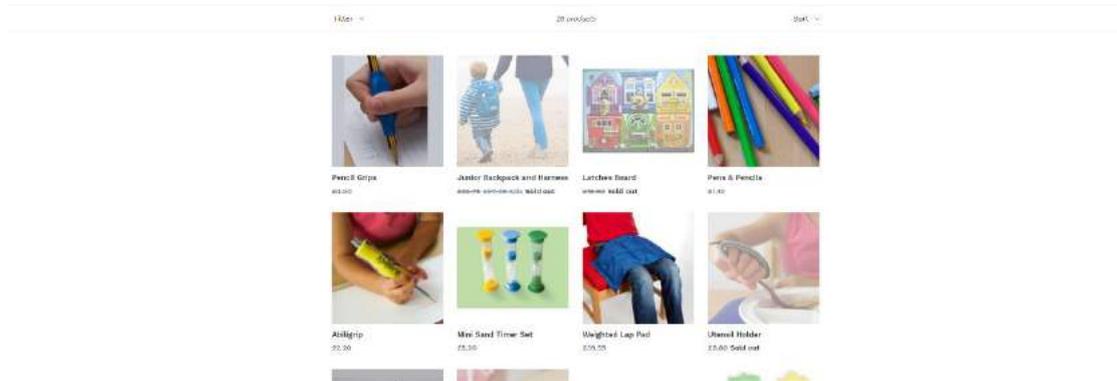
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# Fledglings

## Learning Resources

Often people with additional needs will have a different sensory perception of the world and find it difficult to process the information they receive. To make their lives easier and less stressful, we have developed a range of learning resources and sensory equipment. We continue to introduce products to meet needs.

If you are interested to buy or contact us for further information or support, it will be our pleasure to provide you with the product you are looking for, and we are happy to assist you in the right direction.



After being approached last year, and after careful consideration, Contact recently took over [Fledglings](#), a charity providing practical equipment, aides and solutions for families who care for a child with a disability or additional needs.

Families often don't know what equipment or support is available, and having the right aids can make a real impact socially. We'll be working hard to maintain the Fledglings service, and hope you'll agree that being able to continue to offer these kinds of practical solutions for families is a truly positive step.

Fledglings' service, name and website will remain the same. However, the takeover does mean that families looking for practical products for their disabled child will be able to find over 450 products and 1500 product lines as well as wider information, support and advice - in one trusted place from Contact.

Please share this news with the families in your area with and we encourage families to take a look at the [Fledglings online shop](#) to see the full range of products offered.

## 2019 Annual Conference and NNPCF AGM

We hope to be able to give you a date and location for this year's national event and NNPCF AGM before the end of March so that forums can include a budget for attendance in their 2019-20 grant applications. We'll be in touch soon to confirm.

## Fundraising Webinar

Our Fundraising Webinar has been rescheduled for 12.00pm on Wednesday 13th March. The webinar will include:

- An overview of the potential sources of income available for forums from community events to Charitable Trusts and local authority funding
- What you need to be able to in order to secure funds including how to make the case for support
- Practical advice on how to find out who has funding you can apply for and how to go about applying for it.
- Examples of what other forums have done - if your forum has had some success with fundraising that you would like to share on the webinar, please get in touch with Sarah Lee ([sarah.lee@contact.org.uk](mailto:sarah.lee@contact.org.uk)).

[Register for the webinar.](#)

## Health Updates and resources

Contact's Strategic Health Lead, Lynn Hoppenbrouwers, is collecting and sharing any health related information, consultations and publications that may be relevant to parent carers and forums on the ['News & Updates'](#) page.

Updates this month's include:

- an overview of the recently published NHS Long-Term Plan
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- consultation on Learning Disability and Autism Training for Health and Care Staff
- several relevant NICE guidelines in development and opportunities to sit on the development committee:
  - Epilepsies in children, young people & adults
  - Shared decision making
  - Service model for people with learning disabilities and behaviour that challenges
  - Infant, children and young people's experience of healthcare
- see how your local healthcare organisations, including CCG's are performing using MyNHS website.

If there is any information you think might be useful to other parent carer forums, please forward to [lynn.hoppenbrouwers@contact.org.uk](mailto:lynn.hoppenbrouwers@contact.org.uk)

### Forum participation stories

Did your forum have a positive experience of your SEND local area inspection? Did you manage to save or prevent changes to a service? Has your forum been recognised locally for its work? Let us know if your forum has been involved in a piece of work that has made a difference in your area - we'd like to hear positive participation stories which will inspire, re-invigorate or re-motivate other forums.

### Survey on technology and digital communication for parent carers

The survey is part of a study being conducted by a research team in the School of Allied Health Professions and the Research Centre for Children, Families and Communities at Canterbury Christ Church University. The survey asks questions about how parents and carers use technology - such as phones, computers and tablets - to help them in their role as a carer of a disabled child/children who use occupational therapy, speech and language therapy or physiotherapy services. There are 24 questions. The collective results will be used to help develop a research project on technology for parents and carers and may be used in a research publication. The university does not

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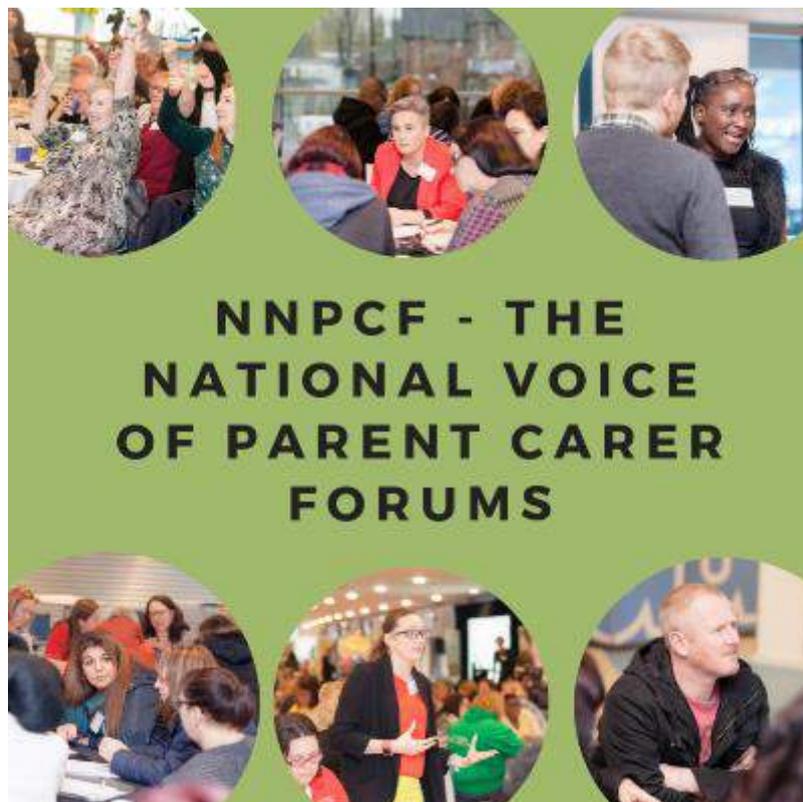
ask for any personal identification, nor will they use any identifying information in any report, article or document.

You can help them by filling in the survey below and by sharing it with your forum members, the deadline is 15th March 2019.

<https://canterbury.onlinesurveys.ac.uk/getting-help-when-you-need-it-a-parent-and-carer-consult>

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### News from the NNPCF Steering Group



### Coproduction & Campaigning - an update

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Following on from the document we produced in coproduction with Contact in July 2018 we have released an update to this. This explores the message given by Prime Minister Theresa May in her response letter to the National Council for Voluntary Organisations (NCVO) request for clarity on the matter of Adverse Publicity Clauses within contracts for centrally funded organisations and charities.

To see the full update, please take a look at our [website](#).

### **National Audit Office Inquiry Response**

The National Audit Office is conducting an inquiry the support for pupils with Special Educational Needs and Disabilities. As part of the inquiry they have invited evidence submissions to be shared with them We have compiled a national response based on information we receive from our member parent carer forums. You can read this in full on our [website](#).

### **Ofsted meet with Parent Carers**

East of England regional parent carer forums invited Lead Ofsted Inspectors to join them to discuss the challenges parents are facing and their concerns about off-rolling pupils, illegal exclusions, and the challenge of 'inclusive' school cultures.

They heard some harrowing stories from families about their experiences, as well as discussing possible ways to improve these situations. Read the [article](#) from the East of England Regional Steering Group Member for the NNPCF on our [news page](#).

### **NHS Long Term Plan**

The NHS Long Term Plan was published in January. We have been involved in some of the engagement events ensuring that parent carers experiences and voices help to shape the plan. We have representatives attending workstreams that feed into this

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programme of activity which we will continue to use as a conduit for feedback. You can read our [full response](#) to see how the plan has responded to your input.

## Meet the NNPCF Team

Do you want to know more about the NNPCF team? We are all Parent Carers to children and/or young people with SEN/D who are part of our local Parent Carer Forums. We each have hectic lives, like you, as well supporting our local communities and regions to participate in the national SEND agenda through our roles in the National Network. Take a look at their individual profiles for more information about the [Steering Group](#) and [National Representatives](#).

## You said, We did...



Regional steering group members have been listening to our member forums, seeking their views, and sharing them with our national partners on your behalf. We have produced some new Talking Point documents in response to these conversations. Please take a look at them on our [website](#).

## Consultations

The NNPCF are currently collating national responses to the following

## Useful Information

- [SEN 2 Data](#)
- [DfE Newsletters](#)
- [CDC Case Law](#)
- [SEND Single Route of Redress \(SEND Tribunal](#)

- *Education Inspection Framework - Ofsted*

Other consultations that parent carer forums may be interested in responding to or sharing with their parent carer communities can be found on [our consultations page](#).

[National Trial\) Guidance and toolkit](#)

- [NNPCF news updates](#)
- [SEND Joint Inspection Outcome Letters](#)
- [Find your Forum](#)

### Did you know that...

SEND Area Inspection Revisits are taking place? So far a handful of revisits have taken place. Revisits are only being made to areas where a Written Statement of Action was issued following a Joint Area SEND Inspection.

The revisits do not represent a re-inspection of SEN provision. Inspectors from Ofsted and the Care Quality Commission (CQC) will only revisit those areas which were asked to produce a WSoA and the focus of the visit will be on the progress made since the original inspection. The revisits are designed to assess the progress which local areas have made against each of the actions in their WSoA. They will also provide additional reassurance to families on the progress local services are making; identify where further work is needed; and enable local areas to demonstrate the improvements they have made to SEND services and in delivering better outcomes for children and young people.

Follow us on [Facebook](#) to keep up to date with inspection and revisit updates.

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