

# AN INTRODUCTION TO PARENT CARER FORUM PARTICIPATION

An introduction to Regional and National Parent Carer Participation.

What part do you and your forum play?

Why is this important?

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# WHAT WILL WE COVER?

- Who are the NNPCF & Contact – what roles do they play?
- Regional and National Structures
  - for forums
  - SEND Leads, Peer Networks, DBOT (delivering better outcomes together), and others
- What support, guidance, and networking opportunities are available for forums?

## WHERE FORUMS BEGAN

- in 2008 Aiming High for Disabled Children was launched
- the DfES made an annual grant available to develop and support Parent Carer Forums so that parent carers would have a strategic voice in the development of services for children and young people with SEND in their local areas and influence services
- for the last 11 years Contact has supported the development of Parent Carer Forums and administered their annual grant from the Department for Education

# WHAT SUPPORT DOES CONTACT OFFER TO FORUMS?

Contact provides:

- A named parent carer participation adviser for each forum able to offer telephone and email advice and support. Face to face support may also be available if necessary.
- Information, resources, support and guidance to forums in relation to the grant process and completion of forms; management of the grant process, including grant application approval and grant monitoring approval.
- An annual event hosted by Contact and the NNPCF, which is open to all parent carer forums.
- Information and resources to support forum's engagement with health partners locally, and routes to provide feedback on parent carer experiences to NHS England and other national health bodies via our Strategic Health Lead.

# CONTACT'S SUPPORT CONT'...

- Intensive support through our associate pool or mediators when significant issues arise.
- At least eight webinars over the course of the year
- Contact has a learning and events for forums page
- Regular news and updates on the issues that matter to forums including good practice examples, consultations, changes to legislation, events etc.
- Contact and the National Network of Parent Carer Forums (NNPCF) produce a termly joint parent carer participation newsletter.
- Complimentary subscription to Community Matters (who provide legal and technical advice, information and support to community organisations) for all parent carer forums to help with governance and legal issues.

# NNPCF WHO ARE WE?

- Membership organisation of 151 local parent carer forums
- 93,000 members
- Core work is around strategic participation of families to getting voices heard and to shape services
- Parent Carer Forums include parent carers with a full range of experiences in Health, Education and Social Care as their children/young people have a wide range of conditions
- We are a parent carer led organisation
- Evidence based
- Solution focused



Paragraph 1.13 SEND code of practice:

*"Parent Carer Forums are representative local groups of parents and carers of children and young people with disabilities who work alongside local authorities, education, health and other service providers to ensure the services they plan, commission, deliver and monitor meet the needs of children and families"*

# WHAT DO WE DO?

Influencing local policy and service design through strategic coproduction



Supporting regional learning and sharing best practice through regional networks



Regional commissioning

Shaping national policy change, informing national developments and improving opportunities for participation



Department for Education



Department of Health



# WE LISTEN TO OUR MEMBER FORUMS

- Attended over 100 regional meetings and events
- Conducted three member surveys
- Sought feedback on 12 consultations and calls for evidence
- Learnt from over 900 discussions and 10,000 comments and reactions on closed Facebook page
- Asked ad hoc questions of members
- Gathered pages and pages and pages of feedback from our 2018 annual conference



# WHAT WE DO & DON'T DO

We Do...



- Represent families' views and experiences
- Collaborate
- Co-produce
- Signpost

We Don't...



- Campaign
- Offer individual support

# THE ROLE OF PARENT CARER FORUMS



Parent Carer Forums are made up of parent carers of children and young people aged 0-25 and should include kinship carers, adoptive parents and foster carers



They are a key strategic partner with their local authority, Health and voluntary sector to ensure that local services and facilities better meet the needs of SEND children, young people and their families

# WHAT FORUMS DO

Forums work with a range of organisations to include parent carers' views, including support and campaign groups to:

- Reach out and promote the forum to all parent carers, including those from seldom heard groups, to provide a range of opportunities for parent carers to share their experiences of local services, both good and bad; to have their voice heard, learn about co-production and build up their skills and confidence to be more involved in the forum by being a member of the steering group or committee, or as a parent representative.
- You should consider building up a bank of evidence to be able to demonstrate and represent the views, needs and experiences of a wide range of parent carers – this can be through informal meetings and discussion, surveys, social media polls, social media comments about posts and day to day contact with parent carers.
- You may choose to put on a range of events and activities to bring parents together to share and learn from each other, learn about any developments, and about the impact of the work the forum does

# WHAT FORUMS DO

- Develop a network of parent carer representatives (as steering group or pool of trained reps)
- Connect with communities to:
  - gather intelligence & evidence
  - demonstrate success
  - share key information
  - promote participation & engagement with parent carers both strategically and individually
- Provide participation opportunities
- Develop & maintain strategic relationships
  - LA – Adults & childrens services (incl. education, skills & learning, and social care teams)
  - Health - Adults & childrens services; Acute care; Community services; Commissioned to PVI
  - Other key partners: IASS; Support networks; Condition specific groups
  - Providers – for example schools & colleges
- Be a critical friend

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You are not there to promote the needs of your own or individual families, or to raise complaints on behalf of individuals

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Parent representatives shouldn't talk about their own personal situations in meetings unless relevant & representative of the wider community's experiences

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You are not a campaigning group – though you can work with campaign groups to provide information and evidence of needs

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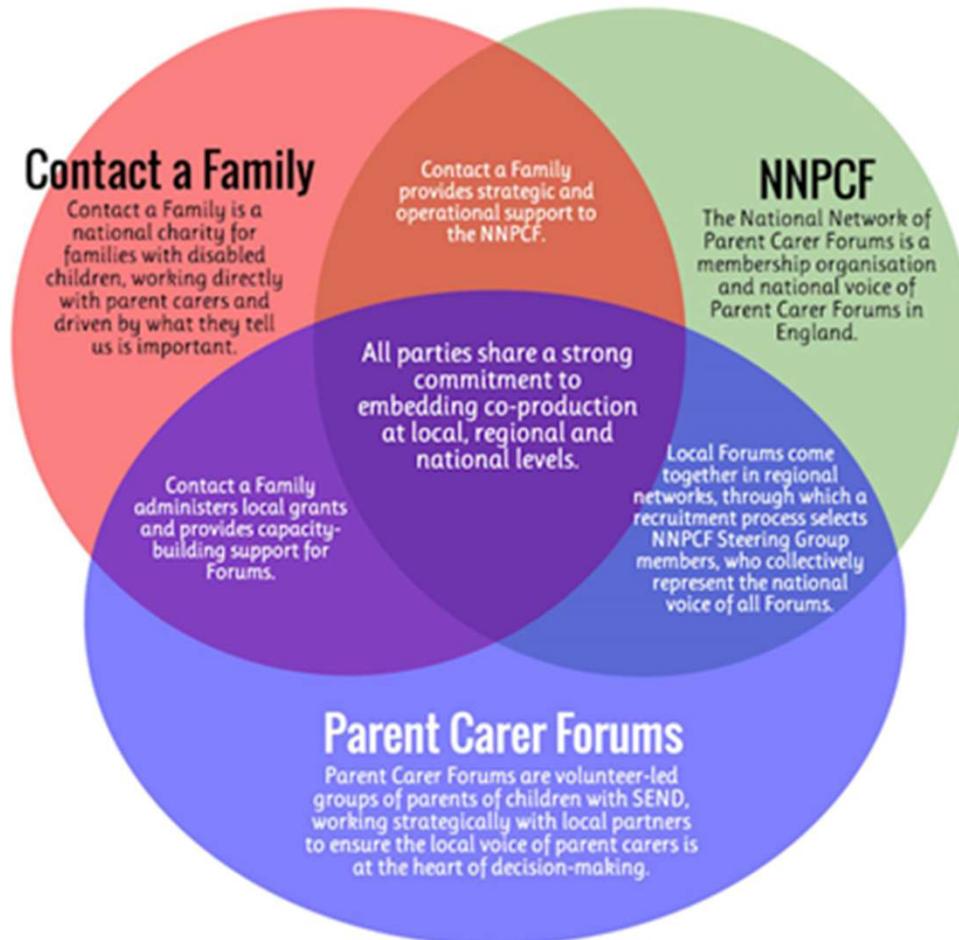
You shouldn't be negative about local partners including other groups and parents – be respectful

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You are not there to rubber stamp local partner decisions or agree with everything that they say

## WHAT FORUMS DO NOT DO

The NNPCF is the national representative voice of parent carers of children with SEND.  
Contact a Family fulfils an enabling and capacity-building role for the NNPCF and local Forums.



# HOW WE WORK TOGETHER

# WHAT IS CO-PRODUCTION?



An equal and reciprocal partnership where everyone's experience, knowledge and skills are used to create better outcomes

# THE LEGAL FRAMEWORK

The requirement to co-produce with children, young people and their parent carers is embedded in primary legislation

- The views, wishes and feelings of the child or young person and the child's parents
- ..participating as fully as possible in decisions and being provided with the information and support necessary to enable participation

The Children and Families Act 2014



- actively promote participation in providing interventions that are co-produced with individuals, families, friends, carers and the community.

The Care Act 2014



- The patient will be at the heart of everything the NHS does
- NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers

NHS Constitution



However, the main reason to co-produce is that it is the best and most effective way of improving outcomes

# INDIVIDUAL AND STRATEGIC CO-PRODUCTION

## Individual

- Parent Carers having their voice heard about their child and engaging with *services that they use*
- Parent Carers working with practitioners, sharing *individual experiences* to improve service delivery for their own family
- Families *engaging* in person centred processes that improve outcomes for them

## Strategic

- Meeting with service leads to share Parent Carers *collective experiences* to improve service delivery for all families
- Forums *working with commissioners, service providers and policy makers* to develop and design services, pathways, and processes to improve outcomes for all children, young people and their families
- Forums shaping and supporting improvement to practices to provide improved Parent Carer engagement *across all services*



### **Regional Parent Carer Forum**

Training Needs  
Priority Work Areas  
Sharing Good Practice  
PCF Representation  
Regional & National Feedback – consultations and reports  
Regional Support Network



### **SEND Leads Network**

Training Needs  
Priority Work Areas  
Sharing Good Practice  
LA Representation  
Regional Support Network  
Cluster Working & Joint Regional / Sub-Regional Commissioning  
DBOT programme delivery  
Peer Challenge



### **Other Networks**

Think Local Act Personal  
Association of Directors of Adult Services  
Association of Directors of Children's Services  
Local Government Association  
IASS



### **Regional Clinical Networks / Other Health Networks**

Transforming Care  
CYP Mental Health – Future In Mind  
Sustainable Transformation Plans & Local Transformation Plans  
Joint Commissioning  
Integrated Care Systems

# REGIONAL STRUCTURES

# DBOT – DELIVERING BETTER OUTCOMES TOGETHER

## National Partners

- NNPCF
- Contact
- Preparation for Adulthood
- Council for Disabled Children
- KIDS
- DfE SEND Unit Advisors
- Mott MacDonald

## Regional Delivery

- Events
- Workshops
- Targeted support
- KPIs
  - Joint Working
  - Integration & Sustainability
  - Coproduction
- Training & Support

# PEER TO PEER SUPPORT FOR PCFS

Forums give each other support through a range of ways:

- Regional Forum meetings
- Online:
  - NNPCF closed Facebook pages
  - Open social media
- Sharing resources, tips, experiences, & successes which can include strategic information as well as be about general governance and forum management
- Championing each others work
- Offering guidance and support in times of challenge



## QUESTIONS?...

"The first step to receiving an answer is being brave enough to ask a question..."

THANK YOU FOR  
PARTICIPATING!

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