

Introducing Parent Carer Forums and parent carer participation



- Each local authority area has a parent carer forum funded by DfE
 Parent forums are made up of:
 - Parents/Carers
 - Grandparents
 - Adoptive parents
- Foster parents
 We recognise all forms of disability which include children with learning difficulties as well as those with
- physical disabilities.
 •You do not need a formal diagnosis to join the forum.

What is Parent Carer Participation?

- Parent carer participation is when parents and professionals work together, recognising each other's expert knowledge, to make informed decisions about children's services that make the best use of people's time and money
- Parent carers can often pinpoint problems frequently experienced by families with disabled children. This knowledge is useful to professionals as they plan services to meet disabled children's needs.

Contact - Parent Participation

What is a parent carer forum (PCF)?

The SEND Code of Practice says: Parent Carer Forums are:

- ✓ representative local groups of parent carers of children and young people with disabilities
- work alongside local authorities, education, health and other service providers
- ensure the services they plan, commission, deliver and monitor meet the needs of children and families





Special educational needs and disability code of practice: 0 to 25 years

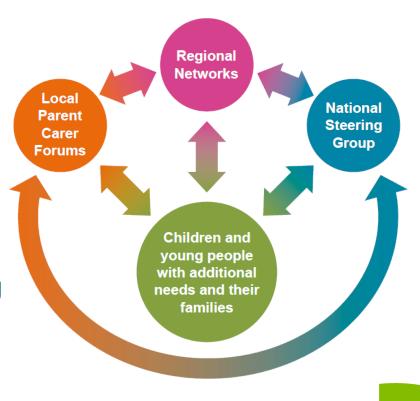
Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities

January 2015

What is the National Network of Parent Carer Forums (NNPCF)?

- The NNPCF is a membership led organisation.
- Made up of (up to) 152 local parent carer forums where they are in receipt of the 'Parent Carer Participation Grant'
- 9 regional representative act as their regional steering group member within the NNPCF national steering group.

http://www.nnpcf.org.uk/



Contact For families with disabled children

- A parent-driven charity covering the 4 nations supporting families with disabled children regardless of condition or diagnosis.
- SEND Reforms Contact a Family is the DfE's delivery partner supporting the development and sustainability of Parent Carer Forums and co-production (since 2008).
- Administration of the DfE Parent Carer Participation grant programme for Forums.
- Contact a Family provides support and advice to PCFs through a Core, and Enhanced Offer.
- Work in partnership with the National Network of Parent Carer Forums (NNPCF).

How we all work together.

Contact a Family

Contact a Family is a national charity for families with disabled children, working directly with parent carers and driven by what they tell us is important.

> Contact a Family administers local grants and provides capacitybuilding support for Forums.

Contact a Family provides strategic and operational support to the NNPCF.

All parties share a strong commitment to embedding co-production at local, regional and national levels.

NNPCF

The National Network of Parent Carer Forums is a membership organisation and national voice of Parent Carer Forums in England.

Local Forums come together in regional networks, through which a recruitment process selects NNPCF Steering Group members, who collectively represent the national voice of all Forums.

Parent Carer Forums

Parent Carer Forums are volunteer-led groups of parents of children with SEND, working strategically with local partners to ensure the local voice of parent carers is at the heart of decision-making.

Co-production

Co-production

Co-design

Engagement

Consultation

Informing

Educating

Coercion

Doing with

in an equal and reciprocial partnership

Doing for

engaging and involving people

Doing to

trying to fix people who are passive recipients of service

Four cornerstones of co-production

WELCOME AND CARE

VALUE AND INCLUDE

COMMUNICATE

WORK IN PARTNERSHIP

Developing and nurturing each of these to build

TRUST

- Contact host the National Alliance for Partnership working (NAPW)
- A group of organisations involved in the national implementation of the Children & Families Act (2014)
- Adopted the approach to coproduction developed in Rotherham

Quality Indicators Self-assessment tool

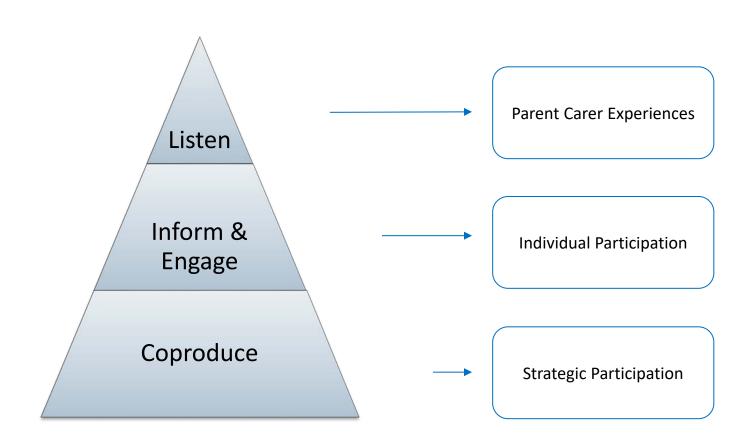
Individual participation

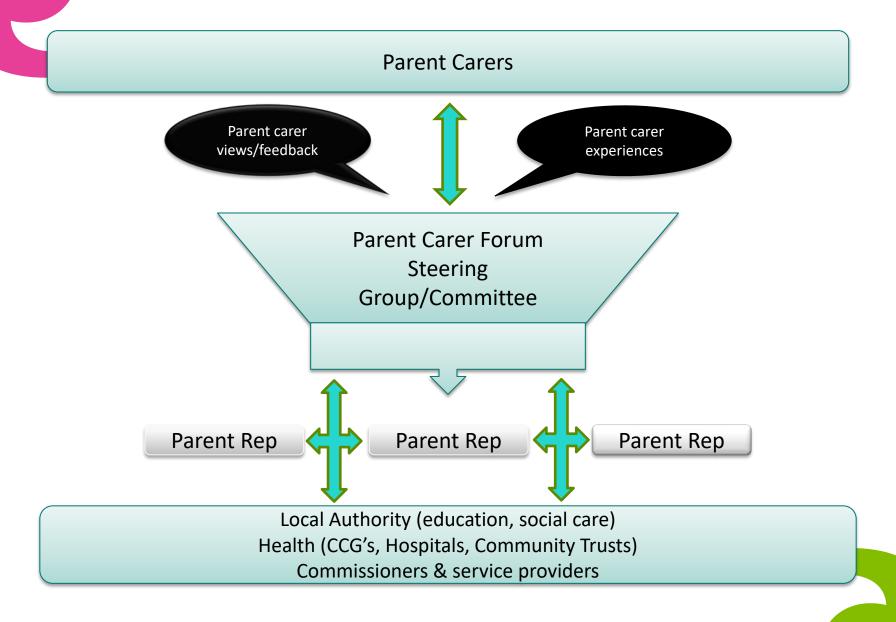
- Parent Carers meeting with practitioners, sharing individual experiences to improve service delivery for their own family
- Individual Parent Carers responding to consultations to inform service design and development of processes and pathways to improve outcomes for their children and family
- Parent Carers having their voice heard about their child and engaging with services that they use
- Families engaging in person centred processes that improve outcomes for them

Strategic Participation

- Meeting with service leads to share Parent Carers collective experiences to improve service delivery for all families
- Forums working with commissioners 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
- Parent Carer Forums coproducing person centred processes to improve outcomes for families.
- Influencing policy and strategic direction as part of the Local Area Team

How do forums work?





Similar approach - Participation & coproduction

People's views come first - especially those who find it hardest to be heard.

We champion what matters to you and work with others to find ideas that work.

We are independent and committed to making the biggest difference to you.

We work just like Healthwatch- why not work together!?

Why work with forums?

- DfE-funded forums are supported by Contact and NNPCF to understand the strategic role they can play.
- Parent Carer Forums are often the one consistent element within the SEND agenda locally.
- They have an understanding of what is happening on the ground for families.
- Forums should be working at a strategic level with ALL area partners so can offer insight into the effectiveness of these strategic mechanisms for participation.
- They have access to information and resources to keep them up to date with national issues relating to SEND
- They are recognised by DfE, OfSted and CQC as the "go to" local source of independent information on the parent carer experience

Long Term Plan SEND

There is a strong focus on improving care for people with learning disabilities and autism.

Commitments include:

- increasing access to support for children and young people with an autism diagnosis,
- developing new models of care to provide care closer to home and investing in intensive, crisis and forensic community support.

The aim is that, by 2023/24, inpatient provision for people with learning difficulties or autism will have reduced to less than half of the 2015 level.

Long Term Plan & SEND

Commits to a significant expansion of services for children and young people in line with the proposals outlined in the Green Paper on young people's mental health -

- the creation of 'mental health support teams' in schools.
- To support these changes, the plan mandates that investment in children and young people's mental health provision will grow faster than the overall NHS budget and total mental health spending

Long Term Plan SEND

Integrated care and population health

The plan confirms the shift towards integrated care and placebased systems which has been a defining feature of recent NHS policy.

ICSs will be the main mechanism for achieving this - the plan says that ICSs will cover all areas of England by April 2021 - and will increasingly focus on population health.

Reducing Health inequalities:

The plan commits to a 'more concerted and systematic approach to reducing health inequalities', with a promise that action on inequalities will be central to everything that the NHS does

Long Term Plan SEND

Participation...Participation...

The LTP states a need to create genuine partnerships between professionals and patients, it commits to training staff to be able to have conversations that help people make the decisions that are right for them.

Nothing new to the Healthwatch Network

It is what we do and it is what Parent Forums do!

A case for collaboration

In Enfield the PCF:

work really closely with their local Healthwatch who champion "Co-production" and both have ensured

the Forum's voice is heard by involving them in all their consultations

Have taken on parents to be volunteers and sessional workers

Parents/Carers are working with local providers such as the North Middlesex University Hospital Trust to deliver disability awareness sessions to staff

Involved local adults with LD/ASD/ADHD and other disabilities as well as parent/carers and young people in sharing their experiences of health services as part of the Long Term Plan initiatives

A case for collaboration

In Rotherham PCF:

work really closely with Healthwatch and meet regularly.

"One particular HW employee was nominated by one of our families at our recent "You Believed in Me" Awards, this person works tirelessly to support families of children and young people with SEND, particularly those accessing CAMHS"

In Somerset Local Healthwatch - Emily Taylor Healthwatch Manager:

"Ruth (Somerset PCF) is another member of the board, where she feeds intelligence from Parent Carers and local issues, which we can elevate both locally and nationally via our reporting."

A case for collaboration

Where things didn't work:

One Parent Carer Forum reported working with their local Healthwatch had been good, because of an individual champion who then left. The relationship was not the same afterwards so it needed some continuity of working together.

Solution: Local Healthwatch to work with the PCF to identify new relationship, better handover of partnerships

"We don't have time for this!"

Solution: If time is made, the time needed is minimal in the longer term, a regular update report, two way flow, ensuring data intelligence is highly valuable and not missed.

Get in touch / get involved

Contact Details of your local Healthwatch can be found here:

https://www.healthwatch.co.uk/your-localhealthwatch/list

- Become a Volunteer for Healthwatch Enter and View visits, Champion, Ambassador roles
- Advisory Groups/Steering Groups where PCF can have a voice at local level
- "Have you told Healthwatch?" Leaflets and referral to local Healthwatch helpline.

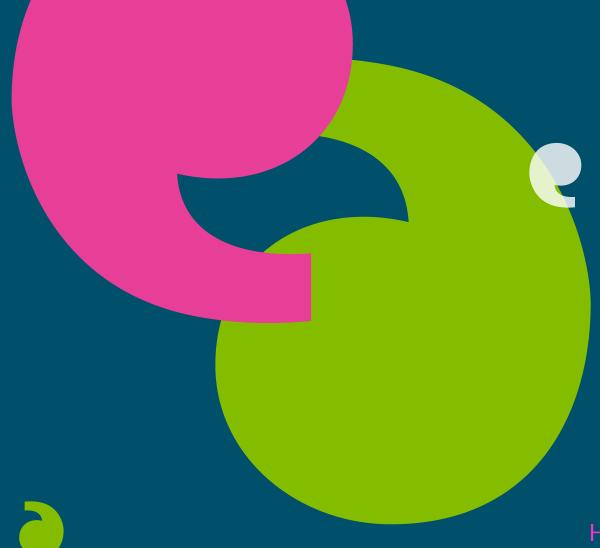
Get in touch / get involved

Contact Details of your local parent carer forum can be found here:

https://contact.org.uk/get-involved/parentcarer-participation/introduction-to-parentcarer-participation/

NNPCF regional representatives can be found here:

http://www.nnpcf.org.uk/about-thennpcf/steering-group-members/



Healthwatch England

Healthwatch England www.healthwatch.co.uk

@healthwatchE

Tel: 03000 683 000