
Introduction to Parent Carer Participation – How you can have your voice heard and get involved!

A Contact/ NNCPF webinar

presented by

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Aims of session

- Learn about parent carer participation, how parent carer forums developed, and how they work.
- Hear about how parent carer forums help to improve services for children and young people with SEND (Special Educational Needs and Disabilities).
- Find out how the NNPCF (National Network of Parent Carer Forums) gives parent carers a Regional and National voice.
- Find out how to get involved in your local PCF.





What is a Parent Carer Forum and what do they do?

Watch this video and find out.

www.youtube.com/watch?v=vcfmJHiGoKw&feature=youtu.be



Parent carer participation can happen in different ways

- On an **individual level** - parent carers influence their own child or young person's journey through services and work with practitioners to ensure the best possible provision and support is available.
- **Strategic participation via parent carer forums** – where local parents have formed a group that aims to ensure that all families with children and young people with SEND have their voices heard and that services meet their needs. Parent carer forums work in partnership with practitioners to design, develop, review and improve services and support for children and young people with SEND in the local area.



Benefits of involving families in service design



- Parent carers can help to pinpoint challenges frequently experienced by families with children and young people with Special Educational Needs and disabilities (SEND) through their experience of navigating services and support.
- They are also able to highlight examples of good practice across education, health and social care (both children and adults) in a local area that is providing support and services that work well.
- Their insights and knowledge are invaluable to practitioners because listening to, and involving, parent carers helps them to improve how services and support for children, young people and their families are delivered so that they better meet families' needs.



What is a Parent Carer Forum?



- The way parent carers work strategically with practitioners is by forming groups called parent carer forums
- A parent carer forum is a group of parents and carers of children and young people (0-25) with additional needs and disabilities.
- Their aim is to make sure the services in their area meet the needs of disabled children and their families.
- Forums usually have a steering group of parents who lead this work and listen to the views of other parents in the local area to make sure they know what is important to them. Forums want to hear from as many parent carers as possible.



What is the benefit of being in a forum?

Benefits for local families

- Reflect back to service providers what it is really like for our children and young people.
- Improve local services so they meet local need
- Input into regional and national policy discussion.

Individual Benefits

- Build confidence.
- Opportunity to use your skills.
- Be part of a team.
- Flexibility around your personal circumstances.
- Network with other local, regional and national PCFs.



The role of Parent Carer Forums today



- Forums exist to fulfil the original remit under which they were established; namely working with local authorities and health services to improve the quality of provision
- Collect views of the wider parent carer community outside of the steering group. They then use these views to feedback to the Local Authority and health service what is working, what isn't and what could make it better
- Forums often facilitate opportunities for parent carers to meet those who provide local services
- Forums are solution focused

**Forums are the strategic partners for Local Authorities
for parent carer voice**



The role of Parent Carer Forums today continued.



- The forum's role is not the same as a support group. Forums do provide opportunities for families to meet and share their views and experiences, this can provide mutual support, but this is not their main remit.
- Forums represent the collective voice of parent carers rather than advocate for individual families.
- Forums are actively working to extend their membership. In each area, any family with a child/young person who has SEND aged 0-25 is eligible to join their local forum, the forum should endeavor to represent a range of needs.



Independence of forums

- Forums receive funding from the Department for Education to support their participation work. Forums have the freedom to use this in the best way the committee decides, providing it meets the terms of the grant. Some forums are also able to get funding from other sources.
- The role of the forum is to be independent. Whatever funding the forum secures e.g. from a local council is done so under these terms. Often the forum and the funder will have an agreement which includes a reference to this such as a Memorandum of Understanding (MOU) or Service Level Agreement (SLA)
- Forums must comply with the GDPR laws. Any information shared via membership forms or surveys are only used the way that it states. Forums will also only be used in a way that ensure anonymity of families unless there is express permission to use it.





- PCFs gather the views of local families of CYP with SEND and work in partnership with local authorities, education, health providers, social care, and other providers to highlight where local services, processes and commissioning is working well, or provide constructive challenge when changes or improvements need to be made.

Forums work in different ways to do this:

- Surveys
- Informal coffee mornings
- Events
- Feedback from individuals via conversations or emails
- Social media and website

They use this information to influence at strategic meetings, reports and co-production opportunities.



What do we mean by participation



- There can be confusion around the participation of children, young people and their families.
- To help explain this, a ladder outlining the different stages of participation was designed by Roger Hart.
- Participation is not a tick box exercise to fulfill a requirement.
- To help us understand what true participation and co-production is, we are going to look at the amber and green areas in more detail.



The role of Information

- The provision of information does not involve a sharing of knowledge or experience. Participation is more than being provided with information on changes that are being made or have been made.
- Knowledge is an essential ingredient in shaping effective services that best meet local needs. It underpins successful consultation and parent carer participation.

Consultation

- Practitioners should consult with parents on existing services, seeking their views on how services can be improved, and good practice shared from other areas.
- Parents should be informed about any proposed changes to a service and invited to give their feedback and raise any concerns about the proposals **before final decisions are made**



Participation



- Effective parent carer participation happens when parents have conversations with, and work alongside, practitioners in order to design, develop, improve, and evaluate services.
- The benefits of participation include practitioners understanding what needs to happen to develop services that meet families' needs, and that parents understand the complexity involved, and the challenges faced by the practitioners who have to bring about that change.
- Working together, and sharing knowledge, enables us to find solutions that work.



Co-production



- Co-production happens when all team members agree outcomes, co-produce recommendations, plans, actions and materials together, as a collective.
- It is an approach which builds upon meaningful participation and assumes effective consultation and information sharing.
- In essence, co-production is a dynamic group process that happens in the room when there is equal value for each participant's contribution.
- Parent carers are not there just to illustrate the experiences of services users, but rather to take some responsibility to help shape future experiences and be an active part of delivering the solutions.



How forums work with other groups and organisations



- Although forums do not work at an individual case level, they can signpost families to useful resources. e.g. SENDIASS, CONTACT, IPSEA.
- Parent carer forums also invite other organisations to coffee mornings and can facilitate events where parents can speak directly to service providers.
- Although forums grant conditions prevent them from campaigning themselves, they might share information about campaigns if it is clear they are raising awareness and are not endorsing it.
- Many forums work with organisations such as Healthwatch or other participation groups to ensure their members' voices feed into workstreams. They may also share information with their membership which is not confidential.



The National Picture

- Each Parent Carer Forum is a member of the National Network of Parent Carer Forums.
- Throughout England the 151 forums are split into 9 regions.
- The regional representatives all form the NNPCF steering group
- The NNPCF has direct contact with the Department for Education, the Department of Health and Social Care and other organisations such as Ofsted, CQC and NHS England. The NNPCF encourages consultation on policy and maintains a good level of communication to influence decisions.

Members of



National Network of Parent Carer Forums
'Our Strength is our Shared Experience'
www.nnpcf.org.uk



You can get involved with your Local Parent Carer Forum

Parents carers of a child or young person with any type of additional need or disability are welcome to join. Joining your forum does not mean you have to commit lots of time.

In most forums you can join and receive information, and then decide if you want to get more involved at your own pace.

You can get involved and support your forum by:

- Sharing your experiences and views through events, surveys, polls emails
- Raising awareness with other parents
- Signing up for newsletters and social media
- Supporting with projects or events
- Attending meetings
- Steering group/committee

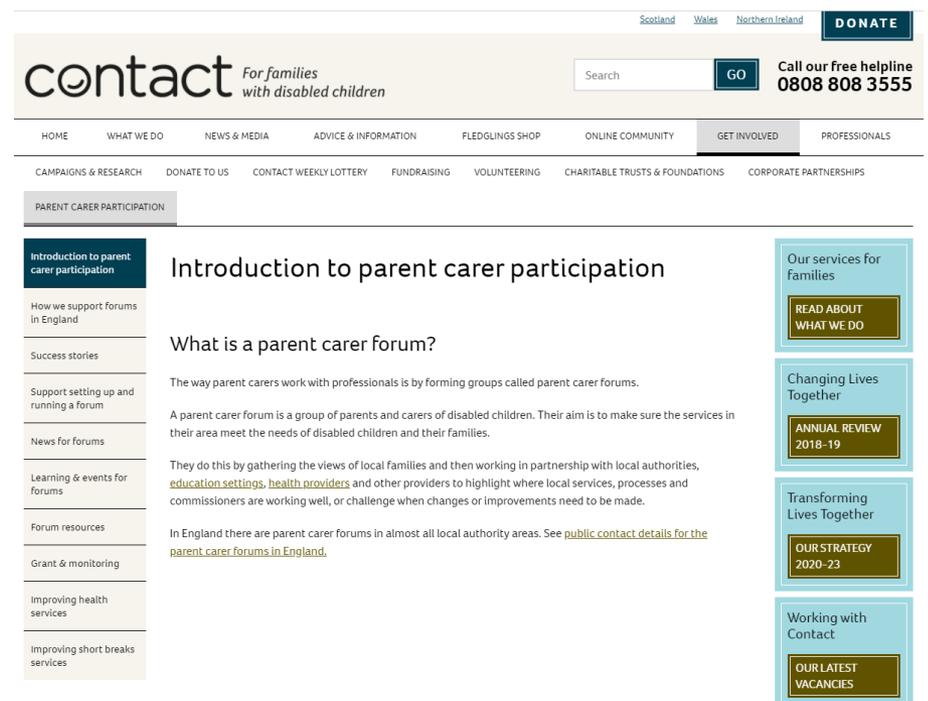


Find your local parent carer forum



The screenshot shows the NNPCF website homepage. At the top, there is a logo with the letters 'N N P C F' in green circles, followed by the text 'National Network of Parent Carer Forums' and a 'Text Size A A A' link. Below the logo is a navigation menu with links for HOME, ABOUT THE NNPCF, GET INVOLVED, USEFUL INFORMATION, NEWS, CONTACT US, and CALENDAR. A large banner image shows a group of seven people smiling. Below the banner is the heading 'Find Your Local Forum' in green. Underneath, there is a paragraph explaining that every local authority area can have a parent carer forum and providing links to regional networks. The regions listed are: North East & Cumbria, Yorkshire & Humber, North West, West Midlands, East Midlands, East of England, London, and South East. On the right side of the banner, there is a search bar and a list of links: NNPCF Structure, Steering Group Members, National Representatives Team, NNPCF National Representatives - Members Page, Overview of NNPCF Activity, Current Activity of NNPCF, Talking Points - NNPCF Key Areas of Focus, NNPCF Key Documents, and News.

<http://www.nnpcf.org.uk/about-the-nnpcf/find-your-local-forum/>



The screenshot shows the contact.org.uk website. At the top, there is a logo for 'contact' with the tagline 'For families with disabled children'. To the right of the logo are links for Scotland, Wales, Northern Ireland, and a DONATE button. Below the logo is a search bar with a 'GO' button and a phone number: 'Call our free helpline 0808 808 3555'. A navigation menu includes links for HOME, WHAT WE DO, NEWS & MEDIA, ADVICE & INFORMATION, FLEDGLINGS SHOP, ONLINE COMMUNITY, GET INVOLVED, and PROFESSIONALS. Below the menu is a list of categories: CAMPAIGNS & RESEARCH, DONATE TO US, CONTACT WEEKLY LOTTERY, FUNDRAISING, VOLUNTEERING, CHARITABLE TRUSTS & FOUNDATIONS, and CORPORATE PARTNERSHIPS. The main content area is titled 'PARENT CARER PARTICIPATION' and features a sub-heading 'Introduction to parent carer participation'. Below this is a table of contents with links to: How we support forums in England, Success stories, Support setting up and running a forum, News for forums, Learning & events for forums, Forum resources, Grant & monitoring, Improving health services, and Improving short breaks services. The main text explains that parent carers work with professionals by forming groups called parent carer forums. It states that a parent carer forum is a group of parents and carers of disabled children, and their aim is to make sure the services in their area meet the needs of disabled children and their families. It also mentions that they do this by gathering the views of local families and then working in partnership with local authorities, education settings, health providers, and other providers to highlight where local services, processes and commissioners are working well, or challenge when changes or improvements need to be made. Finally, it notes that in England there are parent carer forums in almost all local authority areas and provides a link to 'public contact details for the parent carer forums in England'. On the right side of the page, there are four boxes with links: 'Our services for families' (READ ABOUT WHAT WE DO), 'Changing Lives Together' (ANNUAL REVIEW 2018-19), 'Transforming Lives Together' (OUR STRATEGY 2020-23), and 'Working with Contact' (OUR LATEST VACANCIES). At the bottom right, there are social media icons for Facebook and Twitter.

<https://contact.org.uk/get-involved/parent-carer-participation/introduction-to-parent-carer-participation/>



We know that

- Parent carers of children and people with SEND may need to use lots of different services to get support for their child and themselves.
- When parent carers meet other parent carers they often find they are facing similar problems with accessing services.
- Parents in a few areas of England set up a forum (sometimes called a Parent Carer Council) to improve how services were run.

These groups approached their local authority and health service offering to work with them to try to make things improve



**THE BEGINNING
OF FORUMS**



THE GROWTH OF FORUMS



- 2008 launch of the Aiming High for Disabled Children programme.
- Since 2008 parent carer forums have been set up in most local authority areas in England.
- 2014 SEND reforms and parent carer forums became part of the 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. Parent Carer Forums have been established in most local areas and local authorities are actively encouraged to work with them. SEND Code of Practice 1.13



Why? Participation and the Law

Local authority functions: supporting and involving children and young people

In exercising a function under this Part in the case of a child or young person, a local authority in England must have regard to the following matters in particular—

- (a) the views, wishes and feelings of the child and his or her parent, or the young person;
- (b) the importance of the child and his or her parent, or the young person, participating as fully as possible in decisions relating to the exercise of the function concerned;
- (c) the importance of the child and his or her parent, or the young person, being provided with the information and support necessary to enable participation in those decisions;
- (d) the need to support the child and his or her parent, or the young person, in order to facilitate the development of the child or young person and to help him or her achieve the best possible educational and other outcomes. – **Children and Families Act 2014, Section 19**



Participation and the Law cont...

- **SEND Code Of Practice 1.13** 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. Parent Carer Forums have been established in most local areas and local authorities are actively encouraged to work with them.
- **2.6** Local authorities should involve children, young people and parents (including local Parent Carer Forums and Youth Forums) in the design or commissioning of services providing information, advice and support in order to ensure that those services meet local needs. Local authorities should do this in a way which ensures that children, young people and parents feel they have participated fully in the process and have a sense of co-ownership.



Participation and the Law cont...

Under section 14Z2 of the NHS Act 2006, each CCG **must** exercise its functions to secure that individuals to whom the services are being, or may be, provided, are involved in planning commissioning arrangements, in the developments and consideration of proposals for change, and in decisions affecting the operation of commissioning arrangements where implementation would have an impact on the manner in which services are delivered or the range of services available.



Resources

Video - An Introduction to Parent Participation

www.youtube.com/watch?v=O9Pf-JsFuJk&feature=youtu.be

Video - Make a Difference: Why Should I Join My Local Parent Carer Forum?

www.youtube.com/watch?v=vcfmJHiGoKw&feature=youtu.be

Contact your local parent carer forum [here](#)

For more information visit

www.contact.org.uk/get-involved/parent-carer-participation

www.nnpcf.org.uk

