

Terms of Reference

Reviewed 28th April 2014

The purpose of the PaCC is....

To represent Parent Carer members in making a positive difference to the planning, delivery and monitoring of services, so that they enable children and young people and their families to flourish.

The PaCC is...

The PaCC is a forum representing Parent Carers of children or young people with special educational needs and disabilities (SEND) who access key services in Brighton and Hove. (The additional needs may include learning disabilities, mental health needs, physical disabilities, complex or long term health conditions and other additional needs).

The PaCC is part of a regional and national network of 151 other parent carer forums that make up the National Network of Parent Carer Forums (NNPCF). PaCC representatives are members of the SE Regional network and attend regular regional meetings. The NNPCF and PaCC are supported to share best practice locally, regionally and nationally by Contact A Family and receives a the DfE Participation Grant.

PaCC operates within a governance system so that parent carer representatives are trained and supported. In line with best practice we aim to work in duos to add value to our role as members of decision-making groups, and to ensure a range of views are expressed, and to share expertise and support.

The aim of PaCC is...

The PaCC aims to work in partnership with organisations to raise the standard of services and support for Parent Carers and their families in order to maximise our children's opportunities to flourish.

Objectives

1. To research and gather the collective experiences, concerns, views and solutions of parent carer members and provide a way for parent carer representatives to participate in local decision making and influence the planning and delivery of services.
2. To build skills, confidence and teamwork of parent carers so that together we raise awareness of a wide range of children and family's needs.
3. To develop a best practice approach to running an effective parent carer forum.

4. To be representative of, and to work with, all parent carers including groups who may find it harder to be involved or heard, such as single parents, Black Minority Ethnic (BME), Lesbian Gay Bisexual Transgender (LGBT), families facing multiple deprivation, foster parents, and those for whom English is not their first language.

PaCC members are...

Members of PaCC are people with parental and carer responsibilities for a child/young people with additional needs who live in, or access key services in, Brighton & Hove. The PaCC welcomes members from all communities across Brighton & Hove.

How to become a member of PaCC

Standard form to sign. Form to include:
details about c/yp, permission to access information on Amaze/PaCC database (tick boxes), data protection statement detailing how information provided will be used and stored.
parental skills or experience to offer group,
interest in which 'participation' activities
equalities monitoring form

A clear route to opting out of PaCC will be detailed at the end of emails/newsletters to members.

The PaCC Approach and Ethos

The PaCC is a membership-based, parent-led forum. An elected Steering Group make the collective decisions about the policies and procedures, work plans and budget management.

We value the diverse expertise, opinions and experience of all parent carers and young people with additional needs, and seek to use their contributions, time and commitment effectively.

- The PaCC takes a collaborative approach to build positive relationships with our partners and other professionals in order to bring about improvements in service design and delivery.
- The PaCC will provide an honest but constructive approach to challenging partners and professionals to improve the levels of service for our children.
- The PaCC acknowledges that service provision can be constrained by budget and available resources but is committed to improvement of services, using research (national and local) to provide evidence for the cost-effectiveness of such improvements

Recognising the Time, Effort and Work of Parent Carers

As a parent carer forum the PaCC, in collaboration with Amaze, have developed a Parent Carer Engagement and Recognition Policy that remunerates its parent carer volunteers at standard rates for different levels of work.

The Link with Amaze (see PaCC & Amaze Partnership agreement)

The PaCC is supported by Amaze through shared facilities and administration.

Amaze provides a variety of intelligence data from its strategic and service delivery activities that is used in part to inform PaCC policies, priorities and activities.

Grants made by organisations for the purpose of running a Parent Carer Forum within Brighton, are managed by Amaze to employ the part-time posts of Parent Participation Worker and Co-Chairs.

Our Partner Organisations

The PaCC wants to represent the voice of the widest possible number of parents and the diversity of special needs. A number of PaCC Partner organisations also support families in the city. A 'Parent Rep' from each Partner is represented on the PaCC Steering Group. Some PaCC

Partners receive a small amount of funding from the PaCC (as part of our grant with the CCG) to input parent carer views about health services.

Decision Making and Planning

- The PaCC is run by a steering group of a maximum of 18 PaCC members whose experience is representative of the spectrum of the children and young people's special needs and disabilities.
- The group meets five times a year to review the latest information from boards, partner organisations and other PaCC activities to decide the key PaCC priorities and messages.
- The Steering Group divides into smaller sub-groups to provide feedback, and to work on documents and discrete projects. However decisions regarding strategic direction are made during full Steering Group meetings.
- Decisions are made by the Steering Group using the principle of majority vote. These are recorded and minuted at Steering Group meetings.
- Representatives of Amaze, including the Parent Participation Worker, are invited to attend Steering Group meetings, but do not have voting rights.
- The strategic direction, and action plans are decided by the Steering Group, guided by the wider membership, following consultation with individual members and partner organisations.
- The Co-chairs, with support from the Parent Participation Worker, have responsibility for ensuring delivery of the plan.
- The appointment processes for Steering Group members, the co-chairs are detailed in the PaCC appointments policy.

The Key PaCC Activities to Meet the Objectives

1. Core Internal Activities

- **Internal Governance:** This includes updating key documents, election of steering group members, AGM, Steering Group structure and responsibilities, policies and procedures.

- Steering Group meetings: 5 per year. This is the forum for strategic decision making, as detailed above
- Finance: A subgroup of 2 Steering Group members meet twice a year with the Parent Participation Officer to keep up to date with the budget and communicate this with the full Steering Group.
- Training: All new Steering Group members will receive training, and there will be on-going training for all members.
- Membership. As part of its internal governance the steering group ensures a regular process to update and review its current membership. This includes an annual analysis of membership, including the c/yp conditions, BME and geographical profile.
- Recruitment: the PaCC is committed to increasing its membership, in particular those groups who do not typically engage with the forum.

2. Core External Activities

- Parent Representatives: Steering Group members sit on strategic boards/groups and subgroups run by the Brighton and Hove City Council and the Clinical Commissioning Group (CCG) to provide the parent/carer perspective and obtain the latest information on service provision to disseminate to others.
- Feedback: following any Parent Rep work, the key points are fed back to the Steering Group and the wider membership
- PaCConnect: 3/4 forum events a year to bring together parent carers and service providers to promote a service or discuss a current service issue. This is funded by the DfEducation.
- Newsletters: The PaCC publishes six ebuletin (PaCChat) each year to inform the PaCC members and contributes to a PaCC section to the termly Out of Amaze newsletter.
- Website and social media: The PaCC has a website (paccbrighton.org.uk) and makes use of online social media to communicate with members but recognises that this is not a universally accessible communication channel. Ideas for new types of communications, such as apps, are considered.
- Members will be consulted annually to gather views on key issues and routes to participation. This could be done in the form of an email/newsletter, providing information on what has been covered over the preceding year, and asking members to choose (from a list) their key issues for the coming year.
- Regional Meetings: The Co-chairs attend regional meetings, accompanied by another steering group member. This is funded by the Department for Education.
- Information pack: A welcome back/PaCC information pack is given out to new members.

3. Additional Activities

- Parent Carer Partnership Charter: The PaCC has developed, with service providers, the Parent Carer Partnership Charter to help providers focus on eight areas of best practice to consider when working with disabled children and their parent carers. Parent Assessors review services with the providers to discuss

recommendations for improvement and to create a plan of action to adopt the recommendations.

- Calendar: A calendar is produced before Christmas to send to members. This is funded by the DfEducation
- Interview panels: PaCC members sit on interview panels for key roles working with disabled children within the city.
- Research: Every two years the PaCC undertakes a major research project, writing an in-depth report on parent carer views on a particular issue or service sector. The report is used to lobby for improvements and progresses tracked by the PaCC Reps. Previous reports have included 'More Therapies' 'SEN Education' and 'Talk Health'.
- PaCC Awards: Annual awards for nominated professionals. This is funded by the DfEducation
- Steering Group Social Meetings
- PaCC Partners. Using the partner organisations to gather information about health matters among their membership. This is funded by the CCG.

How is PaCC Funded

PaCC is currently funded by grants from three key partners: the Brighton and Hove Clinical Commissioning Group, Brighton and Hove City Council and the Department of Education (via Contact A Family). We have service specifications which set out what we are expected to do for this funding.

The budget is managed by the Parent Participation and Outreach Officer. A sub-group of at least two steering group members is responsible for understanding the budget and communicating this with the remainder of the steering group. The steering group is responsible for deciding how the budget should be spent, within the limits of the service specifications set out for each grant.