



Terms of Reference - Brighton and Hove

Our purpose is:-

To develop a single forum representing parent carers of children or young people with any condition (learning disabilities, physical disabilities or complex health needs). The Parent Carers' Council (PaCC) aims to maximise our children's opportunities to flourish by working with all organisations to champion equality and raise standards of services and support for carer families.

Our objectives are:-

- To improve services so that they become more family focussed, responsive to individual need and preventative where possible.
- To build skills, confidence and teamwork by individual parent carers and between parent carer groups so that together we raise awareness of our children's needs and recognition of our role as parent carers.
- To be representative and to work with seldom heard groups of parent carers.
- To develop and build good practice mechanisms to engage with service users better.
- To ensure that children with complex, moderate or severe needs are able to access the high quality specialist and inclusive services that they require.

We value an honest and constructive approach that can identify problems, use creative ways to find solutions, and build meaningful partnerships. We value the expertise of parent carers and young people with additional needs, and seek to use their contributions, time and commitment effectively. We acknowledge that sometimes new ways of working must be found within existing resources.

Terms used

- The term 'parent carers' means any person who has carer responsibilities for the child/young person in addition to their parental role. This includes adoptive parents, foster parents, step parents, grandparents and others.
- Parent carers are welcome from the every diverse and multicultural community across Brighton and Hove.
- The Parent Carers' Council is available for anyone who lives in Brighton & Hove, or whose child/young person accesses key services in this area.

Co-leaders of the Parent Carers' Council (PaCC)

Steering group members will elect from nominations two parent carers to jointly lead the PaCC. Initially, one person will stand for 1 year, the other for two years, so that there is an overlap and consistency in leadership in the future. There will be remuneration for the hours of work at agreed rate.

Steering Group

Any one can attend the steering groups where the planning of future events and key discussions take place. These meetings will be held at least every two months (for about 2 hours), and the agendas and minutes made available to everyone. As the group develops we will decide further policies and procedures.

Wider membership

In our first year parent carers can join the PaCC by completing a simple form and joining the communication list. We would also invite organisations lead by or who work closely with parent carers to join as organisations. This will help us involve more parent carers, co-ordinate our efforts more effectively, avoid duplication.

Activities

We will work with partners and funders to plan engagement and consultation events and respond to specific consultation or engagement events. However, as a proactive group, each year parent carers will vote upon which issue to prioritise. Activities will be related to that topic and fit in with any other relevant work in the city. Activities will be chosen to include as many parent carers as possible and a final report by the PaCC will be presented to the key decision making groups. The PaCC report will record:

- how parent carers' experience and understand the "issue"
- what already works well (their view of examples of good practice)
- what needs further improvement and why
- specific recommendations (SMART goals¹) for improvements

Once the report has been presented, the PaCC will work with commissioners, partnership boards, service providers and others to deliver the service change. This work will continue after the year end but regular progress reports will be distributed to keep all parent carers informed. Effort will be made to capture how the PaCC has made a difference.

Recognising time, effort and work by parent carers

As part of good practice, as recommended in Reward and Recognition 2005 (Bec Hanley, Department of Health), parent carers will be offered standards rates for different levels of work. This includes attendance of the steering group and other key decision-making boards or events. The rates of pay will be monitored and regularly reviewed, and parent carers given clear guidance about to manage this income with existing benefits etc.

Partnership working with Amaze

Amaze provides important administrative support and partnership for the PaCC (see document 'Roles and Responsibilities'). As a new group, we need the ongoing assistance and support from Amaze, which is the key independent organisation already providing impartial advice, support and information to parents of children with any special need in Brighton & Hove. However the PaCC seeks to actively engage with and represent a wider group of organisations therefore the PaCC will have its own elected representatives on key decision making groups.

Working with funders

Funding for the PaCC is from Brighton & Hove City Primary Care Trust (£15,000 2007-2008), and is to facilitate consultation about health issues, and £5,000 from the Disabled Children Strategic Partnership Board to engage with the Aiming High for Disabled Children programme. The PaCC will seek more long term contracts and additional funding from other sources in order to develop its activities.

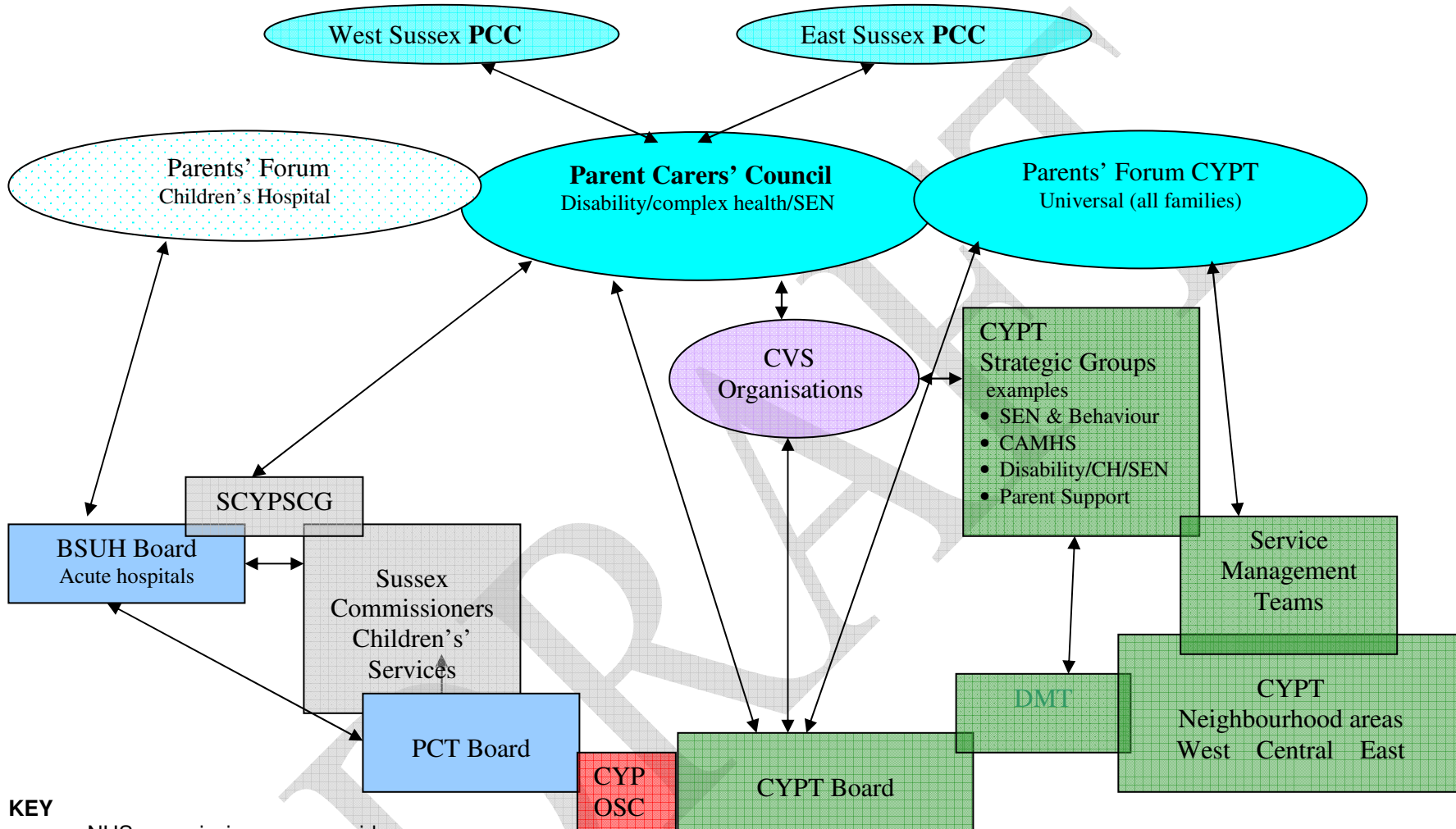
Working with partnership boards and other groups

The PaCC will provide an elected representative to decision-making groups and seek to support each representative with the information and training to promote the views of parent carers and the PaCC. Each representatives' time and work will be remunerated and the host organisation should cover this cost wherever possible. We would also provide advice and training for new groups beginning to work with parent carers.

¹ SMART goals include S- specific, M-measurable, A-action-based (achievable), R-realistic, T-time framed

Organisation Context

Brighton & Hove Parent Carers' Council



KEY

- NHS commissioners or providers
- Children and Young People's Trust: including groups with strategic and decision making responsibilities
- CYPOSC = Children and Young People's Overview and Scrutiny Committee
- Sussex wide groups (SCYPSCG =Sussex Children and Young People's Strategic Clinical Group)
- DMT = Divisional Managers Team CYPT(?)
- Denotes main relationships, not all
- Denotes bidirectional relationships
- PCT Brighton & Hove City Primary Care Trust (NHS Commissioners)
- BSUH Brighton & Sussex University Hospitals Trust (Acute NHS service providers)