

Useful Documents

This contains various forms and documents in by parent carer forums that other forums might find useful when developing their own.

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Mission Statements

A **mission** statement sets out the groups aims and what they hope to achieve. This is important as it ensures everyone involved in the group understands its purpose. It can be useful to display them on websites and newsletters – to give a clear message to people what the purpose of the organisation is.

Below are some examples from existing parent carer forums which might help when deciding your own.

Welcome to the Waltham Forest Parent Forum

We are a friendly, voluntary group of parents and carers of disabled children and young people aged from 0 to 25 in the London Borough of Waltham Forest. Our aim is to provide feedback on the development and direction of services for disabled children and young people in the borough to key policy makers..

Welcome to the Sheffield Parent Carer Forum Website!

We are a group of parent carers of children with a wide range of disabilities. Our aim is to give parent carers in Sheffield a voice in influencing local developments that affect their children.

Norfolk Family Voice Family Voice is a collective of parents and carers of children with special and additional needs working voluntarily and 'Aiming High'.

Our aim is to make sure that parent's voices are heard when it comes to planning and decision making about services for our children in Norfolk.

Terms of Reference

Terms of Reference will set out the purpose and structure of the forum including:

- what it hopes to achieve
- roles and responsibilities (i.e. who will take part in it, what will they do)
- how often meetings will be held
- who will attend
- how representatives will be selected
- how decisions will be made

-

Terms of Reference do not have to be complicated. It is useful to think about them early in the life of the forum. They can be updated as the forum develops.

They will need to be tailored to fit the ways of working adopted by a forum and should always be discussed and agreed by members.

An example of a terms of reference sent in by Brighton Amaze can be found on the next page. .



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, mental health need, 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.

Open membership for individuals, *associate membership by relevant organisations*

In our first year any 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 with 'Associate' membership.* This will help us involve more parent carers, co-ordinate our efforts more effectively, and avoid duplication.

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.

We will need to ensure that the membership of the steering group is representative of the wider community of parent carers including all age and special needs, all mainstream and/or special schools they attend, all areas and sectors of our community and involvement with other relevant organisations. As part of the work plan, a matrix can be developed to help the steering group stay as representational as possible.

It is recognised that our children have multiple abilities and needs and the left hand column denote the main but not only characteristic. Also, real life means that this table records a target and a tool. Our families are more complex that a 'box' can ever define.

<i>Child/ young person age</i>	<i>0-4 years</i>	<i>5-11 years</i>	<i>12-15 years</i>	<i>16-19 years</i>	<i>20-25 years</i>
<i>Learning difficulty</i>					
<i>Physical disability</i>					
<i>Mental health</i>					
<i>Complex health</i>					
<i>Emotional and behavioural</i>					

It may be helpful to ensure that at least a third of parent carers on the group have links with other relevant organisations, or are formal representatives from those organisations.

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

Steering group members will elect from nominations from the group two parent carers to jointly lead the PaCC. Initially, one person will stand for 1 year, the other for two years, (maximum term is 3 years) so that there is an overlap and consistency in leadership in the future. There will be remuneration for the hours of work at an agreed rate.

Nicola Gibson and Debbie Collins were elected joint co-chairs in November 2008. After drawing lots, it was agreed that Debbie Collins would be available for re-election in November 2009, and if elected could sit for a further two year term. Nicola Gibson would stand down in November 2010, and could be available to stand for a further year.

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.

A table showing the different levels of involvement and rates of pay are shown in appendix One.

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

Partnership working with Amaze

The Parent Carers' Council is the initiative of Amaze, and a project within it. 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.

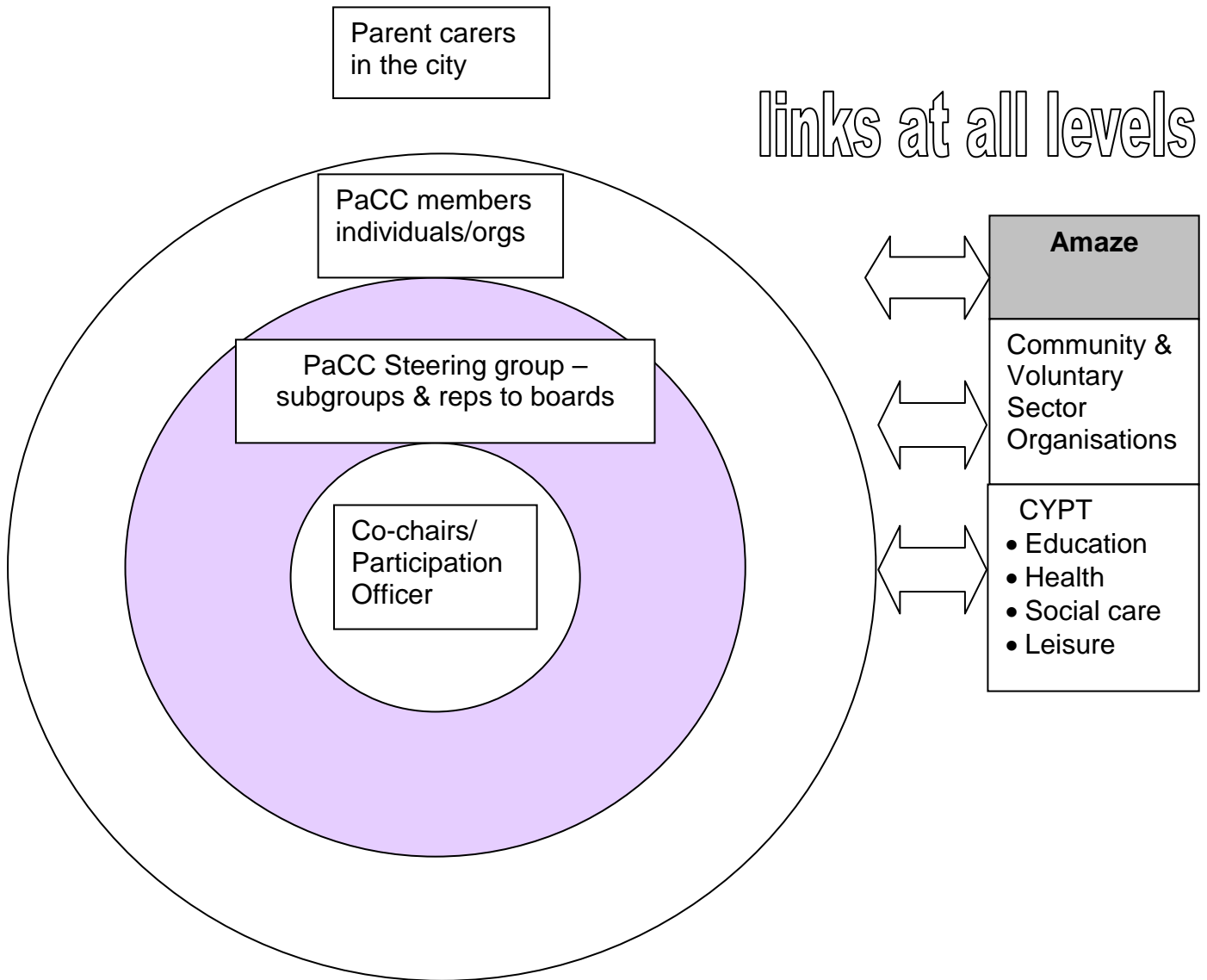
Working with funders

Funding for the PaCC is from Brighton & Hove City Primary Care Trust (£15,000 2009-2010), and is to facilitate consultation about health issues, and £5,000 from the Disabled Children Strategic Partnership Board to assist 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

In time 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.

Brighton Amaze – Diagram of forum structure and links to other organisations



Parent Carers' Council Payment and Reimbursements Table

The table below shows different levels of involvement and related reimbursement.

	Involvement Activity	PaCC Example	Payment	Amount
Level 1:	<ul style="list-style-type: none"> • Simply informing people of what is planned or has already been decided • Consulting on decisions, offering opinions, listening to feedback <p>Voluntary, unpaid work</p>	<p>Open invitation meetings,</p> <p>1st Birthday update event</p> <p>folding, distributing</p>	Expenses only	Expenses with receipts
Level 2:	<ul style="list-style-type: none"> • Deciding together, encouraging additional ideas or options, seeking joint decisions • Acting together, not only deciding jointly what to do, but actually doing it together "in partnership" • Encouraging proactive initiatives. Helping others to do what they want – within an agreed work plan and framework of advice and support provided by those who are responsible for the resources. • Assisting interviewing process as observer 	<p>PaCC Steering group</p> <p>Sub groups – maximum of two per year</p> <p>Rate for elected representatives</p> <p>Focus groups</p>	Payment at lower rate plus expenses	£10.00
Level 3:	<ul style="list-style-type: none"> • Contribute to academic activity, training/educating others work, involving extensive preparation such as presenting at a seminar or conference. • Undertaking work with a higher level of responsibility, or requiring a particular level of expertise. • <i>Interviewing with full decision making role</i> 	<p>Co-chairs,</p> <p>No more than 4 hours weekly term time only</p>	Payment at medium rate plus expenses	£12.50
Level 4:	<ul style="list-style-type: none"> • Delivering work <i>on behalf of Amaze, like running training courses.</i> • <i>Co-facilitating or leading training</i> including co-ordination and administration of workshops 		Payment at higher rate plus expenses	£15.00

Norfolk Family Voice – Data Protection Policy DATA PROTECTION POLICY

Family Voice Norfolk will fully comply with the Data Protection Act 1998 and Data Protection principles, which state that information must be:

- o Fairly and lawfully processed
- o Processed for limited purposes
- o Adequate, relevant and not excessive
- o Accurate
- o Not kept longer than necessary
- o Processed in accordance with individuals rights
- o Kept secure
- o Not transferred without adequate protection

Family Voice Norfolk recognise that the above principles relate to both paper and electronic systems of record keeping.

This information will not be disclosed to any other party, unless with specific permission of the person it relates to. Any person may request that their details are removed from our records at any time. Any person may request a copy of their information at any time.

The membership database may not be e-mailed under any circumstances.

The membership database may only be held by the Steering Group or staff who have signed this form.

I agree to abide to the principles and rules of this policy.

Signed -----

Position-----

Date-----

Parental Representation Agreement Form

The Aims of Family are :

- To represent families of children with special or additional needs by providing a liaison point for Statutory and Voluntary Agencies within Norfolk.
- To consult with and inform our membership of outcomes and updates of our representational work.

These aims are stated in our constitution.

Parental Agreement

I agree to represent Family Voice in a courteous manner at all times.

I agree to abide by the aims of Family Voice and represent families on behalf of Family Voice.

Print Name _____

Signature _____

Date _____

Steering Group member

Print name _____

Signature _____

Date _____

PACC Committee Members Statement of Responsibility

As a member of the PACC Committee I accept that:

I am liable for any damage or loss to my own personal property that I use whilst going about PACC business.

I am responsible for ensuring that I am safe whilst travelling on PACC business, and for ensuring that safety of any passengers in my car. In any accident I would be able to claim on my personal car insurance.

I am responsible for my own safety whilst going about PACC business.

I will not:

- use PACC to further my own interests/beliefs or the interests/beliefs of any other agency or organization (statutory, voluntary or commercial)
- use PACC to represent my own view to the exclusion of the views of other parents/carers
- as a member of PACC, offer individual case work or counseling, but will signpost people to relevant organizations who can offer this.

I will hold in confidence all matters that come to my attention including information about any person or organisation that comes to my attention as a member of PACC, except in those cases where there is permission to share information.

I will respect the privacy of other members of PACC.

I will use all information gained as a member of PACC in a responsible manner.

I will read and follow the contents of the PACC Handbook.

Signed

Name

Date

MEMBERSHIP FORM



1. About You								
Name(s)								
Telephone Number			Mobile		Email Address			
Would you like information sent by:		email?	<input type="checkbox"/>	large print?	<input type="checkbox"/>	Text?	<input type="checkbox"/>	
Where did you hear about us?								
Address								
			Postcode					
Do you or your partner (if any) have a disability or special needs? If so please specify:								
<input type="checkbox"/>	Please tick if you receive a means-tested benefit. We sometimes have special grants we can pass on to you.							
2. About Your Child								
Child's Name								
Gender:	Male	<input type="checkbox"/>	Female	<input type="checkbox"/>	Age:	D.O.B:		
School			Mainstream	<input type="checkbox"/>	Special School			<input type="checkbox"/>
If your child has any siblings please state how many:				Brothers		Sisters		
D.O.B:								
Does your child have a Statement of Special Educational Needs				Yes	No	Applying		
3. Ethnic Monitoring								
White British	<input type="checkbox"/>	White/Black Caribbean	<input type="checkbox"/>	Indian	<input type="checkbox"/>	Black Caribbean	<input type="checkbox"/>	
Irish	<input type="checkbox"/>	White/Black African	<input type="checkbox"/>	Pakistani	<input type="checkbox"/>	Black African	<input type="checkbox"/>	
Other White	<input type="checkbox"/>	White/Asian	<input type="checkbox"/>	Bangladeshi	<input type="checkbox"/>	Other Black	<input type="checkbox"/>	
Chinese	<input type="checkbox"/>	Other Mixed	<input type="checkbox"/>	Other Asian	<input type="checkbox"/>	Other	<input type="checkbox"/>	

4.	More About Your Child
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The next section will help us to provide you with the right information. Please complete as much or as little as you wish.

Does your child have:	Physical disability	<input type="checkbox"/>
You can give us more information about your child in this space if you wish.	Learning disability	<input type="checkbox"/>
	Sensory impairment	<input type="checkbox"/>
	Complex health needs	<input type="checkbox"/>
	Mental health issues	<input type="checkbox"/>
	Other	<input type="checkbox"/>

5.	Which Health services does your child use?
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Social Services

Short Breaks/Outreach <input type="checkbox"/>	Who provides this?	Wheelchair Services	<input type="checkbox"/>
Community Support Services	<input type="checkbox"/>	Other (please specify)	<input type="checkbox"/>
Linden Brook	<input type="checkbox"/>		
Mencap	<input type="checkbox"/>		
Other (please specify)	<input type="checkbox"/>		

Do you have a social worker? Y/N	Other support?
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Support Groups/Networks Your Family Use or Belong To

National	<input type="checkbox"/>	Please say which:	
Local	<input type="checkbox"/>	Please say which:	

Please use this box to give us any further information which you think may be useful:

I consent to this information being used by the Parent & Carers Council. This information will not be shared with any other organisation without my permission.	Members Signature:
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Part Two

Monitoring information

This information is anonymous and will not be traced to you or your answers on the questionnaire. We have a duty to show that we are reaching a diverse group of parents (for example, showing that we are not a single issue campaign group). The information will not be stored in any database or records, and will be destroyed once the report about the survey is published.

About your child/children with additional needs:

child one	female <input type="checkbox"/>	male <input type="checkbox"/>
child two	female <input type="checkbox"/>	male <input type="checkbox"/>
child three	female <input type="checkbox"/>	male <input type="checkbox"/>

Your child/children's age:

child one	child two	child three
<input type="checkbox"/> 0 - 4 years	<input type="checkbox"/> 0 - 4 years	<input type="checkbox"/> 0 - 4 years
<input type="checkbox"/> 5 -11 years	<input type="checkbox"/> 5 -11 years	<input type="checkbox"/> 5 -11 years
<input type="checkbox"/> 12-15 years	<input type="checkbox"/> 12-15 years	<input type="checkbox"/> 12-15 years
<input type="checkbox"/> 16-19 years	<input type="checkbox"/> 16-19 years	<input type="checkbox"/> 16-19 years
<input type="checkbox"/> 20-25 years	<input type="checkbox"/> 20-25 years	<input type="checkbox"/> 20-25 years

Your child/children's main condition:

While we understand it is sometimes difficult to summarise your children's main needs, it would be helpful if you **could tick one or more** of the areas that most closely relate to your child/children.

Child one	child two	child three
<input type="checkbox"/> Learning disability	<input type="checkbox"/> Learning disability	<input type="checkbox"/> Learning disability
<input type="checkbox"/> Emotional/Behavioural	<input type="checkbox"/> Emotional/Behavioural	<input type="checkbox"/> Emotional/Behavioural
<input type="checkbox"/> Physical disability	<input type="checkbox"/> Physical disability	<input type="checkbox"/> Physical disability
<input type="checkbox"/> Mental health needs <input type="checkbox"/>	Mental health needs <input type="checkbox"/>	Mental health needs
<input type="checkbox"/> Complex health needs	<input type="checkbox"/> Complex health needs	<input type="checkbox"/> Complex health needs
<input type="checkbox"/> Other.....	<input type="checkbox"/> Other.....	<input type="checkbox"/> Other.....

About You

Your gender: female male

Ethnicity:

White British
 Irish
 Other

Black or Black British African
 Caribbean
 Other Black background

Asian or Asian British Bangladeshi
 Indian
 Pakistani
 Other Asian background

Chinese

Mixed White & Black Caribbean
 White & Asian

 White & Black African
 Other mixed background

Any other ethnic group

Do you consider yourself to have a disability?

Yes No

Sexuality:

Please select the option that best describes your sexuality.

Lesbian Heterosexual
 Gay Bisexual

Thank you so much for filling this form in.

We look forward to seeing all of you at our information event on.....

LINCOLNSHIRE PARENT CARER COUNCIL

GENERAL EXPENSES CLAIM FORM

Name and address of person claiming re-imbursment of funds:	
Name and Address where cheque should be sent (if different from above)	
I wish to claim £..... Reimbursement of funds as broken down:	
	Amount Claimed (£)
Mileage: miles @ 40p per mile (please complete overleaf for mileage only)	
Attendance allowance: Up to 2 hours £10 Up to 4 hours £20 Up to 6 hours or more £30	
Car Park Fees:	
Stationery/Photocopying Costs (up to £5 for each workstream attended)	
Childcare Costs.....Hours @ £6.25 per hour:	
Other Costs:	
TOTAL AMOUNT CLAIMED	
Please attach all receipts to claim form	

I certify that I have incurred the above costs

Signed: (claimant):	
Please print name here:	
Signed:	

Journey Details

