



National Network of Parent Carer Forums
'Our Strength Is Our Shared Experience'

Engage

Enable

Empower

Progress report
National Network of
Parent Carer Forums

January 2013

Purpose of this report

The purpose of this report is to provide background information about the National Network of Parent Carer Forums (NNPCF). In particular we give an account of our wide range of activities, achievements and partnerships established over the past twenty four months and since the publication of The SEND Green Paper: Call for Views (September 2010).

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“ We would like to thank all the Steering Group members (past and present) and local forum representatives who have contributed to this report. Thank you to our wonderful partners and colleagues. A special thank you also to Sue North and the ‘Strengthening Parent Carer Participation’ team. ”

Carrie Britton and Sarah Thomas,
co-chairs NNPCF Steering Group



National Network of Parent Carer Forums
‘Our Strength Is Our Shared Experience’

contact a family
for families with disabled children

Contact a Family is the delivery partner for the Department of Education ‘Strengthening Parent Carer Participation Programme’

Executive summary

This progress report describes our activity to consolidate a new national organisation at a time of fast moving multidimensional change. All our established sector colleagues report this scale of change as ‘once in a generation’ and unprecedented in its complexity as changes in local government functions, SEND reforms, benefit reforms, and a major health service reorganisation is all happening at the same time.

Each of these changes impacts families of children and young people with additional needs and has proved a huge challenge for all of us personally and professionally. While the changes add anxiety and uncertainty for workers and families alike, we are determined to forge effective partnerships and pursue smarter ways of involving the widest range of parent carers in the processes that shape the reforms. This year forums report that a total of 52,531 parent carers have actively inputted their experiences into their local forums.

Our main focus is to embed local pan disability, parent led parent carer forums and build parent carer participation based upon good practice. Our mission is to promote and model parent carers speaking for parent carers at local, regional and national levels. Working with Contact a Family we are endeavouring to provide the training and support mechanisms for all forums as they become increasingly representative, inclusive and influential in making a difference for local families.

Our experience mirrors that of local forums in our transition from a collective of individual parent carers into a fully constituted and governed organisation. As a national organisation we have been developing effective regional networks and our strategic working relationships which now form a sound operational basis for the future. We believe we have made remarkable progress in this short space of time, due to the commitment of parent carers across England, and the hard work and effort of many.

Our internal activity has therefore focussed on agreeing and consolidating our governance ‘from scratch’. We have worked hard to keep the voice of local parent carers at the forefront of what we do and use the regional network meetings and communication tools to be informed by, and to inform local parents. This report outlines the main policies we have agreed with the remainder being completed by the end of June 2013. Our activities include engagement with the SEND Pathfinders, and with the developments in non Pathfinder areas. For example we held a highly successful event on the 8th February, for representatives from the 31 forums in Pathfinder areas, hosted by the Department of Education. The report of the key learning points will be shared with non pathfinder forum in our national event on 18th March.

Our key relationships are with Contact a Family who hold currently the Department of Education ‘Strengthening Parent Carer Participation Programme’ contract, through which we receive our basic funding. Our work to support and strengthen local forums is supported by the CAF participation team under the very experienced and insightful leadership of Sue North. Our other key relationships are with the Council for Disabled Children and the Department of Education and Department of Health.

“The National Network of Parent Carer Forums has spoken with increasing confidence and authority over the past year. It has felt as if they have a greater sense of the broad views they are representing and I’ve been impressed with the contribution of individual NNPCF members in contact with Ministers and senior officials in a range of forums.

I particularly valued NNPCF’s contribution to the select committee process – both in getting their view on the reforms out to forums and in arranging and encouraging parent carers voices to be heard during the select committee evidence gathering.”

David Chater, Department for Education

The other external relationships we especially value are with the Council for Disabled Children and its member organisations. We also work closely with and contribute to the work of the Special Educational Consortium, and many other delivery partners and organisations.

Our next steps include:

- 1. Preparing our Constitution**
- 2. Consolidating our operational governance**
- 3. Continuing to develop and embed key partnerships**
- 4. Improving our digital and written communication resources (website redevelopment already underway)**
- 5. Facilitating an increase in the administrative support**
- 6. Completion of the selection process for the remaining regional representative posts, and non-regional members to the steering group.**



Part One: Context and organisation

Background

In England during the Aiming High Programme there was a consensus that Short Break services matched local families needs best where parent carer forums had been centrally involved with the design and commissioning of these services. In summer 2009, as part of the Parent Participation Programme, Contact a Family working with the parent carer who had sat on the Ministerial Implementation Group, Anna Gill invited a group of experienced parent carers (each of whom had established effective local parent carer forums) to meet to test the possibilities of developing a national network of forums.

The group's aim was to enable a mechanism for parent carers' views, experiences and solutions to more powerfully and effectively influence local, regional and national policy. In April 2010, the National Network of Parent Carer Forums was launched, and the steering group was formed comprising a representative from each of the nine regions formed and one non regional representative (Anna Gill). We were able to facilitate responses from forums to the Call for Views and other consultation processes. Lively discussion and debate have lead to the following aims, core values, core business, structures, processes and partnerships.

Aims

The aims of the National Network of Parent Carer Forums (NNPCF) are:

- to ensure that good practice, knowledge and shared expertise about parent participation continues to grow and strengthen,
- to develop a cohesive and coherent structure to sustain and develop the effectiveness of parent carer forums across England,
- to strengthen the pan disability, parent lead model of local forums and boost our collective voice.

www.nnpcf.org.uk gives more information.

Core values

The diversity of the regions and range of local parent carer forums is a strength and we have agreed core values to bring consistency and clarity of intent around our primary task of building effective and meaningful participation. These core values have helped shape our decisions, behaviours and plans and are:

About the parent carer voice

- we actively promote the parent carer led approach which is solution focussed and constructive
- we model and promote parent carers speaking for parent carers at all levels
- we promote understanding that parent carers have an independent and unique voice and promote recognition of their skills and experience
- include all parent carers and others who have carer and parental responsibility (foster carers, adoptive parents, grandparents etc).

About the forums and network of the NNPCF

- parent carers' engagement is valued, planned and resourced
- parent carer led and solution focussed
- pan disability parent carer forums linked with effective two way communication with wider parent carer community
- constructive partnerships where parent carer participation is evident throughout planning, delivery and monitoring stages with authentic co-ownership of work
- parent carer forums participate in regional networks and are well linked to local single issue or condition specific groups
- transparent written forum governance including clarity about function of forums, representatives roles, offering support and training opportunities and encouraging use of 'Reward and Recognition and Remuneration' policies
- Ongoing outreach to build inclusive representation including different ethnicity or race groups, faith groups, rural and urban communities, lesbian, gay and transgender groups and recruit wider memberships and partnerships.

NNPCF Core Business – agreed November 2012

In the NNPCF, our function is to build the structure around which we;

- promote and facilitate parent carer participation and coproduction
- provide leadership and model good practice
- listen to and communicate effectively with key partners and local forums
- promote parent led activity
- gather experiences “on the ground” which guides all of our work
- secure a future for local parent carer forums and the NNPCF.

Operational budget

Our operational budget for 2011/2012 was £81,000, and for 2012/2013 was £87,720. We have benefitted also from in kind support from Contact a Family within the ‘Strengthening Parent Carer Participation Programme’. The in kind support includes a free meeting venue and part time operational input from Sue North, Director of Operations. Despite this limited initial budget our team’s achievements have been remarkable.

Relationship with Contact a Family (CAF)

We have valued the support from CAF, and their commitments to assist us develop as an independent organisation in the medium term. We will have progressed our journey towards independence by finalising our constitution by June 2013 in partnership with the regional and local forums. CAF has been especially helpful to us during this development phase. While we work closely and especially value the considerable support from Sue North, Programme Director, we decide on a case by case basis which activities we undertake jointly or which we do separately as two distinct organisations. We are in active discussions with CAF and have produced a Letter of Understanding which awaits being signed off by both parties.

Sue North, Director of Operations, Parent Carer Participation Programme (CAF) contributed the following to this report;

Contact a Family, initially in their role as part of Together for Disabled Children, and then as the Department for Education’s delivery partner supported the development of the National Network of Parent Carer Forums, and continue to offer support to the NNPCF via operational support from the Director of the Programme, and a small amount of support as required for basic administration tasks.

NNPCF and Contact a Family work together closely to support the delivery of the whole of the Strengthening Parent Carer Participation Programme. NNPCF members sit on the Programme Board, which oversees the delivery of both the Contact a Family and Impact Short Break programmes, and also co-chair the National Link Group to promote participation with our other national voluntary and community sector partners. Whilst Contact a Family have clear delivery commitments in relation to the Parent Participation Grant, and individual forum support, the NNPCF work closely with Contact a Family to review and consider these processes, and plan for the future.

Contact a Family Parent Carer Participation Advisors work closely with their NNPCF regional representatives in order to ensure the roles remain complimentary for local forums.

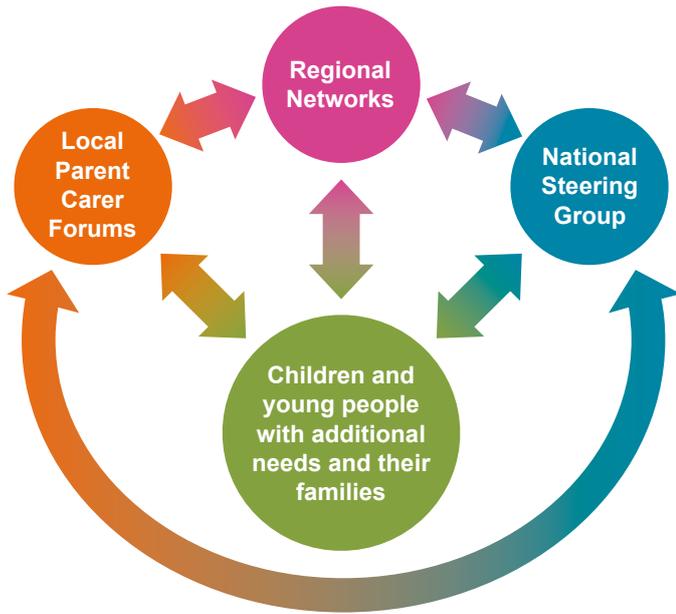
The NNPCF have taken a clear lead in ensuring the voice of parent carers is heard FROM parent carers at a national level, and have established themselves as a credible and valued organisation who are able to challenge, support and develop national agendas, as well as supporting regional developments.

The strong establishment and embedding of the National Network of Parent Carer Forums has been, and is essential for ensuring meaningful parent carer participation locally, regionally and nationally, and Contact a Family are pleased to continue to work as partners with the NNPCF as we administer the Parent Carer Participation Grants, and continue to offer a range of support to parent carer forums locally.

Membership and structure of the NNPCF

About the 151 Parent Carer Forums

The NNPCF membership consists of 151 local parent carer forums that are pan disability, parent led and supported by the Department of Education. Our members are the local forums.



About the NNPCF steering group

The NNPCF steering group has been comprised of ten regional representatives and one non-regional representative. We elect our two co chairs (currently Carrie Britton and Sarah Thomas). We have a second London representative to reflect the large number of authorities represented within London, and also in light that much of our national participation activity occurs in London, and so this helps our capacity to contribute to London based meetings. By January 2013 we will also have undertaken a selection process in five regions and look forward to the remaining regional roles undergoing the same selection process (see website for selection process details and representative criteria). We also look forward to filling the three non regional roles which will considerably strengthen our specialist expertise and capacity.

We are also aiming to select three non regional representatives who will each have a specific remit, e.g. policy, induction and support.

Data from recent grant monitoring returns (CAF)

Forums different kinds of governance arrangements

- Registered Charity
- Community Interest Group
- Social Enterprise
- Constituted Group

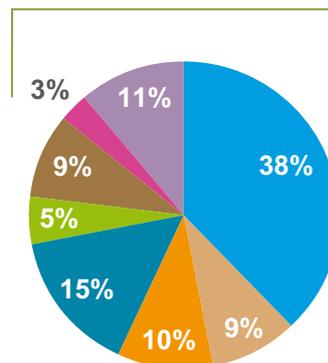
Numbers of parent carers involved

2011/12		2012/13	
Number of parent carers management/steering group involved in running the parent participation work/forum	1,408	Number of parent carers management/steering group involved in running the parent participation work/forum	1,570
Approximately how many parent carers input their experiences of services to the parent carer forum?	31,373	Approximately how many parent carers input their experiences of services to the parent carer forum?	52,531

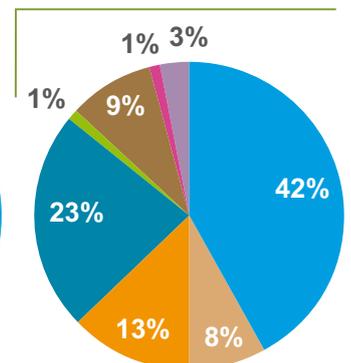
Forums description of their forums

- Independent parent carer led organisation
- Parent partnership service
- Parent carer led organisation supported by parent partnership service
- Voluntary organisation
- Parent carer led organisation supported by local authority
- Local authority
- Parent carer led organisation supported by voluntary organisation
- Other

2011/12



2012/13



About regional representatives

Each regional representative is given a standard annual honorarium for a basic 23 days work commitment (no holiday or sick pay entitlement). In the past two years, the programme have 'paid' for 23 days X 10 representatives = 230 days per year which is less than one full time post (equivalent 260 working days). In order to establish the organisation, most representatives work several times this amount of days unpaid. This is unsustainable in the long term.

About the nine regional networks

All the local forums meet in regional networks at least once a school term, with each region developing slightly different arrangements for these meetings. The purpose of the regional meetings is to ensure that parent carer views have growing influence and impact. We achieve this by building multidimensional communication, joint working, and by developing good practice in participation and coproduction.



Updates from each regional network (February 2013)

North West Region:

Sherann Hillman from Stockport

The North West is a large geographic region with 23 parent carer forums, Cumbria in the extreme North decided to join the NE regional network. Meetings have been held since 2010 with fluctuating attendance ranging from just 7 forums to 16 forums. The average attendance is around 25 representatives, not always from the same forums and meetings are held once per term in different locations around the region. The Region is now starting to establish a more formalised structure and advanced planning for meetings has been the priority.

At the RN meeting in September 2010 the NW region consulted on the Green Paper and submitted a large collated response as the region felt very strongly that their voices needed feeding into central Government. Other meetings have included presentations on the Green Paper and Next Steps document; Early Support and keyworking; training opportunities etc. Forums also use the meetings to network, update each other, share ideas and opportunities.

The NNPCF's presence and profile in the region has increased in recent months and forums are much more aware of the work that we do. In partnership with CAF we continue to build on the foundations which have been laid. It was encouraging to hear how much the forums are valued by strategic partners at the regional event in October; this gave a real boost to all areas.



North East Region:

Johanna Smith from North Tyneside

Originally made up of 12 parent carer forums the North East welcomed Cumbria as the 13th forum in the region in 2011. As many families in the north of Cumbria use specialist services/ hospitals in Newcastle it was felt that in many ways they had a closer link with the North East. Regional meetings are held half-termly in Newcastle upon Tyne as this is the most central point in the region. It has good transport links and the meetings are supported by the regional CAF office who provide free meeting space, lunch and a minute taker. The format and location of meetings is regularly on the agenda. It has been agreed by the region that no regional chair would be appointed and that the NNPCF regional representative would chair the meetings. Additionally the format of these meetings in other regions has been discussed. The majority of forums preferred meetings each half term at a fixed central venue where all 13 forums attend/ receive minutes to the region forming smaller clusters with less frequent regional meetings. The forums in the Teeside region being the exception forming a small cluster (of 4) in 2012, which meets more regularly to discuss specific local issues. The Teeside forums continue to be regular attendees of the regional meetings and feedback on the benefits of their cluster work is good.

The agenda for the regional meetings reflects activity nationally, regionally and locally. Forums contribute local updates during the meeting but are also asked to provide written reports in advance of the meeting when the agenda is particularly full. The focus is on sharing good practice and supporting participation across the region. Where forums are facing challenges these are discussed and solutions explored.

Regional strategies are also discussed – such as developing a regional brand and identity for the regional forum and introducing a regional Facebook page for steering group members. This has proved an excellent way for forums to update each other on their activity and achievements and has also been a helpful way to discuss national priorities between regional meetings. The page is used regularly by most of the forums.

West Midlands Region:

Sarah Thomas from Shropshire

The West Midlands Regional Network includes fourteen local parent carer forums, representing a range of diverse geographical areas, from very rural to one of the largest urban conurbations in the country. The Regional Network meets three times a year and is chaired by a regional chair, elected on an annual basis. Our current chair is Jayne Stevens from the Telford Forum 'Parents Open Doors'. The Network meetings move around the Region, ensuring that parent carers who can't travel due to their caring responsibilities, get a chance to participate in the Regional Network by attending a local meeting. The host forum(s) cover all the meeting costs ensuring that all forums are actively involved in the Regional Network and promoting a sense of ownership. All Forums submit a brief highlights / lowlights report for each Regional meeting whether they are able to attend the actual meeting or not, along with identifying any particular issues they are currently facing. These reports provide a starting point for discussions at the Regional Meetings and give a structure to the information sharing that is a key role of these events.

The Region also uses the meeting to invite speakers to provide information on topics that are identified by the Forums as current. The Region has so far been visited by the local Contact a Family team, Early Support and the Solihull Pathfinder Team. We have also has a specific session looking at working with the new Heath structure in the Region. The opportunity to share successes and challenges is really valued by those who attend the Regional meetings and we are looking forward to developing this further by establishing a regional Facebook page in the near future. Other benefits of the Regional meetings identified by its members are;



“ Being part of a bigger structure that means we have a route to influence Government from the ground upwards and we have seen the difference this makes. ”

“ It is important for identifying shared issues across the region – to show parent carers that they are not alone and to provide a bigger voice. ”

“ It inspires us ”

East Midlands Region:

Dave Nutting from City of Leicester

The East Midlands Region whilst hosting the smallest number of areas at only 9 covers a very large geographic portion of the country. The forums have worked hard to ensure that they are accessible to the diverse ethnic and religious population of this region which includes dense urban populations and large rural areas each with their own seldom heard communities. The open and inclusive forums have attracted a far more representative membership. They have demonstrated the changes that forums can bring and the commitment they have to ensuring every parent carer of a disabled child has an equal voice in developing the local services that affect their lives.

“ I had the opportunity to attend with couple of Somali parents/carers to find out the work of the Forum and how Somali parents and carers maybe involved in the forum who were impressed with the level of participation and engagement among parents and carers in involving in decision making processes of the services they get from the Local Authority. Somali parents/carers who have formed a small forum for themselves and sent a representative in the main Leicester City Parents and Carer’s Forum.

I believe it is very important to recognise that the forum is a venue of relief, an information point and an environment one can feel he/she is not alone.”

Parent Carer Forum member

The 9 areas meet 4 times a year alternating the venue to ensure maximum participation. Our regional advisor and a representative of the NNPCF are always invited and we meet with a simple agenda to share information and best practice, build on the strengths of those who have developed good working relationships with their local authority and use these examples to help improve other areas. The NNPCF and regular speakers help our forums have the right information about the ever changing and complex nature of Health, Education and Welfare at the right time.

All of our forums have grown in membership and ability over the past 3 years. Many have developed strong relationships with each other whilst working together on individual and joint Pathfinders. Some forums who share borders have now produced a joint newsletter with information on each other’s activities which enables new families to find out about us.

Some forums have worked towards becoming parent led organisations; others have developed from small beginnings to now being at the forefront of consultation for changes that may affect disabled children in their area. Each forum is remarkable in its own rights and all have been responsible for ensuring better lives and opportunities for families with disabled children in our region.

Yorkshire & Humberside Region:

Selection progress underway

The Yorkshire and Humber region is made up of 15 parent carer forums. We hold meetings about every 6 weeks and have a mutual understanding and agreement that areas will host and chair a regional meeting on a rolling basis if they have the capacity and funds to do so. The meetings are usually held between 10am-2pm and include refreshments and lunch (chips and cake – has now become the Yorkshire & Humber tradition!).

The forums in Yorkshire and Humber value the opportunity to meet regionally as we feel it sets a good benchmark for our work locally.

As forums we appreciate the chance to network and share ideas and are encouraged by each other, especially during challenging times. This type of peer support also works well through our regional Facebook page.

We feel that sharing positive outcomes from around the region gives local forums the opportunity to take back and share good practice with their Local Authority and Health partners. We have come to realise that by sharing the regions innovative practice with our own local authorities that it can create some healthy competition, this can work wonders in moving along specific pieces of work that may have become stagnant or lost direction.

As a region we feel it is vital to have ongoing and positive communication between ourselves the National Network and Contact a Family. This is especially important as it gives us the direct line we need from parents to Westminster and back again. We would like to express our gratitude as a region for giving us this link as it does ensure the voices of parents are heard locally, regionally and nationally.

“We feel it’s important for people to know that we are part of a National Network and that we are trying to make a difference for future generations of children and their families. It’s good to know we are part of something bigger.”

“We are the driving passion for all.”

As we continue to develop and share our experiences at regional meetings we would hope that our support of each other and membership to the National Network of Parent Carer Forums goes some way towards securing the future sustainability of local forums in the Yorkshire and Humber region.

Eastern Region:

Karen Woodissee from Norfolk

The East has a well established Regional Network of Parent Carer Forums, which is valued by its’ members. Like the vast majority of the Local Forums in the Region, the Group is entirely parent led and each Forum is represented at meetings by parents, in a couple of areas we also have attendees from Voluntary Sector supporters. The Region is quite disparate; there are a total of 11 Local authority areas, we have two of the smallest Unitary Authorities and one of the biggest County Councils operating in a two tier environment. We have an active Parent Participation Forum in all but one of our Local Authority areas; we hope that the eleventh will be re-established very soon. All Local Forums have a clear focus on being the strategic partner to local government/service providers and the voice of parents within service development, just one has ventured into the arena of providing services directly to families. Over the past year we have taken steps to formalise our Regional Network and have elected a Chair for our meetings, we meet 4 times pa. Meeting agendas are led by the needs of the attendees and provide a much needed place to share and celebrate as well as opportunities to share frustrations and learn from each other! Overall, Parent Carers have a recognised strategic voice at a Regional level, each Forum was represented at the SEND Delivery Partner event and a great deal of feedback was given about how valuable the input of parents had been and how visible we had made ourselves. The Network is represented at the Regional Short Breaks Leads meeting and was able to have most Forums represented at the Early Support Regional Action Learning Network alongside LA & PCT colleagues. We have also been lucky to be able to share learning from the Forum in our Pathfinder Authority.

“As Chair of a member forum and Chair of our Regional Forum I can't stress strongly enough the value we have taken from our regional forum. When I first started attending meetings it was great to hear what other forums were doing and the results they were achieving. This gave me ideas to try with our forum and move forward our relationship with our LA. To then be able to come back to the Forum and tell them how we were doing and to be given support and ideas for moving forward is amazing. Having a direct link through our Regional Representative to what's going on at the highest level allows all the local forums to have a say in what is going on and how the NNPCF responds on our behalf to what's happening within Government. Our Regional Forum is a great place to learn what's going to happen in the future in our NHS Services or what Government are proposing to change with in LA's. It allows us as a group to discuss ideas and find out how other LA are going to respond or what they are already doing. It definitely promotes working together and as things are changing so quickly at the moment it's a great way to stay in touch with other forums.”

Chair – Eastern Region Network of Parent Carer Forums

“It felt wonderful to be in a room with likeminded people, who wanted to improve the system. I felt excited, and intrigued. I didn't feel like a lone segregated voice anymore, I felt like I belonged to a higher purpose. Something more than me, and that somehow, somehow we were going to make a change”

New Representative @ Regional Forum

London Region: Mary Busk from Redbridge and Kay Moore from Bromley

“The Regional Cluster meetings that we attend on a regular basis are extremely useful in many ways. Not only do they enable forums to meet and exchange ideas and update on progress with local projects, we are kept up to date with activities at National level and they are a great opportunity for new committee members to gain experience attending a 'larger' meeting.

Personally, I find them very helpful to be able to bounce ideas off of other groups who – whilst very different in their make up – are dealing with very similar issues.”

Parent Forum member, Bexley Parent Carer Forum

There are 32 Parent Carer Forums in London. It is the largest region in terms of numbers of Local Authority areas and of population size. We have three cluster groups of Forums in London who each meet three times a year – North East, North West and South. Forums share the hosting and chairing of Cluster meetings on a rotational basis. This rotation allows Forums to visit new areas and find out about provision across London.

Forums use these meetings to share information about what is happening in their area, to share ideas and best practice. One example has been in the area of play. Parent Carers in Hounslow identified the lack of suitable places to play and researched and wrote a play strategy. This led to positive local engagement with the Local Authority and to the development of new play provision including in local parks for disabled children. This work has been shared with other Forums and has led to positive outcomes in other areas including Hammersmith and Fulham and Havering.

The NNPCF Steering Group rep shares national updates and collects information at the regional cluster meetings. This is a positive way of engaging directly with Parent Forums and finding out and feeding back directly concerns, issues and positive news about what is happening on the ground. It is also a positive way to influence developments of the NNPCF, including in relation to its communications and website.

There are also lots of positive Forum to Forum contacts outside of these meetings. Information and help can be shared on common issues and joint working and there is regular contact on health issues among a number of Forums in all of the Clusters.

We are also forming a strategic Group for London. This is in its early stages as we want to be able to develop more of a London wide view going forward as happens already in other regions.

“When we meet in our individual Forums we see how parent carers become stronger everyday working together to make a difference. When parent reps join our lovely South London Cluster Group we see how we can strengthen our values by learning and sharing the experiences of other South London boroughs. Parent participation at its absolute best.”

Parent Carer Forum member, London

“North West cluster group has been a lifeline for local parent forums, a wealth and knowledge and willingness to share information and offer of support is second to none and all this brought together by our dedicated NNPCF London rep.”

Parent Carer Forum member, London

South West Region: **Doug Morris from Swindon**

As a group, the South West regional network has continued to meet at least every four months since September 2010. Initially the Group was informally led by a volunteer Chair with support from the South West Regional Representative and the South West Parent Participation Advisor from Contact a Family.

Agendas were initially based to provide continued mutual support for developing parent participation and lately focussed on legislation issues and the Families Bill pathfinder experiences. Meetings have involved presentations from various partner organisations as well as targeted presentations from group members.

One of the most beneficial sections of the meetings has been the ‘round the table’ reviews of individual forums progress. This continues to be as inspirational as it is informative. This part of the meeting offers the opportunity for mutual support about how to achieve success whilst recognising the differing nature of the various Local Authorities in the region; Rural and Unitary.

Based on our geographical area, we have met as close to the centre of the region as possible to accommodate the travel needs of the many groups. This has been a key factor in the success of maintaining the group. We have been able to introduce video conferencing using Skype to enable groups such as the Isles of Scilly to be included; this is likely to be used more extensively in the future. As a Group we also recognise not everybody can attend all of the meetings because of local and personal commitments.

The cost of these meetings has been covered by the hosting forum in the past but we now need to look at a sustainable way forward to ensure fairness of costs is incurred.

During recent meetings the group has reaffirmed its on-going commitment to maintain the regional forum recognising the meetings to be a source of mutual support. The power of the group is that of working together, sharing knowledge and keeping up with the national picture both from a participation perspective and legislation point of view. Organisational issues such as the need for a regional chair or administrator, or a “chair for the day” scenario are being discussed.

At present, there is no doubt about the on-going future of the South West regional forum.

South East Region: **Carrie Britton from Brighton & Hove**

The South East region comprises 19 forums, and they decided to organise themselves into two clusters (North and South) to make travelling to termly meetings more practical. We have a Terms of References across the region. Two centrally sited forums in each cluster agreed to alternatively host and arrange the meetings. The NNPCF rep and CAF Adviser have standard update slots in each agenda. To aid our joint working and sustainability we have a regional kitty which funds meetings and buys in resources or training for the group. Our first joint funded project is a SE resource of examples of our key policies, job descriptions, terms of reference from the South East region and includes good practice templates.

“Having regional meetings has been really helpful to share experiences and learn from each other. It has also helped to hear how the Pathfinder work has impacted on forums other work which may have had to be put on hold: this may be detrimental to some forums post pathfinder. Some forums have joined us through SKYPE which we are getting better at using.”

Comments from South Cluster hosts:
Brighton & Hove Parent Carers Council member



“It is a great help to get together for regional meetings and to share experiences. Often each forum is at a very different stage of development and some are encountering challenges and problems for the very first time. It is helpful to be able to talk to other forums who have worked through these challenges and come out the other side stronger as a result – it is great confidence builder. One of the challenges of these meetings is often getting to grips with what is going on nationally, especially with so many changes taking place.”

Comments from alternate North Cluster hosts:
at REACH Wokingham forum member

Part Two: Working with government departments

Department for Education

We have formed strong links with the Department for Education, keeping a 'critical friends' approach. A representative from the Department meets regularly with the NNPCF Steering Group. This provides a valuable opportunity for the Department to update the Steering Group about progress and plans within the SEND, and other Departmental developments, and provides the opportunity for Steering Group members to feed back views, concerns, and thoughts from parent carer forums in each of the 9 regions.

“The National Network of Parent Carer Forums has spoken with increasing confidence and authority over the past year. It has felt as if they have a greater sense of the broad views they are representing and I've been impressed with the contribution of individual NNPCF members in contact with Ministers and senior officials in a range of forums.

I particularly valued NNPCF's contribution to the select committee process – both in getting their view on the reforms out to forums and in arranging and encouraging for parent carers voices to be heard during the select committee evidence gathering.”

David Chater, Department for Education

The Department for Education also invited the NNPCF to send representatives to sit on the National Advisory Group, and the Pathfinder Advisory Group for the SEND reforms. Currently two Steering Group members represent at these boards, and this is documented later within the report. The NNPCF have also been asked to attend and represent at various other departmental meetings, including a meeting to review the SEN Code of Practice.

The NNPCF have also been invited on several occasions to meet with the Minister, Edward Timpson and his predecessor Sarah Teather, alongside other sector representatives.

The NNPCF were also invited to be part of the initial commissioning for the SEND contracts, so were actively involved in working with the Department in relation to parent participation, short breaks, and parent partnership services, and were also able to offer some input into the Pathfinder selection process.

National Advisory Group

The National Advisory Group's purpose is to advise Government on the implementation of its special educational needs and disability reforms. The role of the Group is to be a critical friend offering feedback and views on the development and implementation of the reforms by;

- Providing feedback and advice on the development of the reform programme as a whole
- Providing expertise and links to networks to contribute to the development of the reform programme
- Identifying and helping to develop ways of addressing the challenges involved in implementing the reforms.

The Group is jointly hosted by the Department For Education and the Department of Health and includes representation from the SEN and Disability Green Paper Pathfinder Advisory Group and the Vulnerable Children Task Group of the Ministerial Advisory Group on the role of the local authority. It also includes representation from a Young People's Advisory Group, established to ensure issues that are important to children and young people are addressed in action to take forward the Government's reforms. The Group meets 3 or 4 times a year and the NNPCF is represented at these meetings by Carrie Britton and Sarah Thomas. This representation ensures that the parent carers voice contributes to the development of the reform programme at a national level.

Pathfinder Advisory Group

This is a national group that provides external advice and expertise to the Department for Education and Department of Health on the Pathfinder programme. It offers an opportunity for both Departments to provide policy updates to a range of national organisations involved in supporting children and young people with SEN and disabilities, along with an opportunity to review the progress of the Pathfinder programme. Individual Pathfinders are regularly invited to present to the meetings and discussion might be focused on different areas of the Pathfinder programme. The Group meets 3 or 4 times a year and the NNPCF are represented by Sarah Thomas and Carrie Britton (as with the NAG). The participation of the NNPCF in this group ensures that the role of parent carers, and in particular local parent carer forums, is recognised in the delivery of the Pathfinder programme objectives.

Department of Health

Whilst we do not have the same extensive working relationships with the Department of Health, we have established some partnerships within the Department of Health, with representatives regularly meeting with the NNPCF Steering Group. Due to the significant changes within the Department, the individuals involved have changed on several occasions, however, we are hopeful that a consistent link with the Department of Health will be shortly established.

NNPCF representatives have given presentations at Expert Panel events for regarding the health reforms and in relation to the Health and Wellbeing Board.

We have two members who are part of the SEND National Advisory Group on SEN and Disability Reforms which meets termly.

In the Department of Health White Paper 'Equity and Excellence: Liberating the NHS' the Government made a number of commitments

to extend the choices people have over their healthcare as part of their stated vision of patients and the public being at the heart of the NHS. In the subsequent consultation 'Liberating the NHS: Greater choice and control' the Department of Health sought the views of patients, the wider public, healthcare professionals and the NHS about implementing the choice commitments. This resulted in the Any Qualified Provider scheme where for some conditions, patients will be able to choose from a range of approved providers, such as hospitals or high street service providers.

Parent Carers involvement in discussions about the role out of AQP initially was limited. The NNPCF represented parent carer views national meetings and met with the Department of Health AQP lead for children. As a result of these discussion the NNPCF able to influence the wording in the national Implementation Pack for Continence Services, had in depth discussions about the delivery of wheelchair services and worked on ensuring that parent carer participation was much higher on the agenda of the AQP team.

Children and Young People's Health Outcomes Forum – Long Term Conditions and Disabilities

NNPCF and Contact a Family held an event in Birmingham on March 28th 2012 at which a briefing and presentation was given on the context and work of the Children's and YP Health Outcomes Forum. The ensuing round table discussions were hosted by CAF or National Network members and were grouped on the following themes: Getting into the health system, getting a quality assessment, getting a quality service and Transition.

The resulting rich source of feedback was collated and written up in detail and then submitted as evidence to the Department of Health in their call for views. Many other Forums and individual parent carers submitted evidence all of which was fed directly into the review team. Subsequently it was reported that this 'wealth of overwhelming evidence' made a huge impression on the Forum members, on the DH team and finally reached the Secretary of State in September. The resultant

Children and Young Peoples' health strategy has had its publication delayed due to the cabinet reshuffle but is now expected in early Spring 2013. To read the NNPCF submission see <http://www.nnpcf.org.uk/news-and-consultations>

Other Departments

Whilst we are invited and have represented at other meetings with other relevant department such as the Department for Works and Pensions, we have had to prioritise our involvement in line with our capacity.



Part Three: External Partnerships

Introduction

The NNPCF promotes a solution focused way of working that is based on constructive partnerships. As a new organisation we are mindful of our need to be fully integrated, informed, effective and contributive to the wider work of the sector while being very clear to promote the values of parent led forums and participation and coproduction based upon good practise. The work and value of local parent carer forums are relatively unfamiliar to some partner organisations, and practicalities that underpin delivery of effective participation, like payment for parent carers contributions and parent carers speaking for parent carers is new practise for some. Therefore we especially value the opportunities that partnership working brings with other organisations supporting families of children and young people with disabilities or additional needs.

A) Working with other organisations

National Link Group

The purpose of the National Link Group is to bring together a range of different organizations within England who are involved in working directly with parent carers so that they can share ideas, good practice and open up opportunities to progress the parent participation agenda as it affects families caring for a disabled child.

Meetings are held termly and chairing is shared between Paul Soames from Contact a Family and Anna Walker (previously South West). A number of objectives for bringing these organisations together were identified, including:



- Ensuring that organizations within the National Link Grouping are kept up to date and informed of the work taking place through the delivery partner for parent carer participation
- Sharing intelligence, ideas and good practice between the organisations who make up the National Link Group
- Considering how organizations can work more effectively together on the parent carer participation agenda so as to provide added value and improved outcomes for parents.
- Sharing challenges, successes, and opportunities so that organisations can support each other.
- Cascading information, ideas and good practice through each organisation so that parent carers who are involved in respective agencies get the opportunity to take part in local, regional and national parent participation activity.
- Looking at future trends and opportunities.

Organisations attending the previous meetings have been keen to learn more about the NNPCF and further their knowledge around the principles of parent participation.

This has resulted in improved efforts within individual organisations to engage with their own parent communities. Additionally there has been wider recognition of the potential and benefit of the NNPCF as a conduit for parent engagement with some specific activity undertaken with local forums as a result.

Programme Board Meeting

The Programme Board is made up of the Directors from Contact a Family responsible for the Parent Participation Programme, the Directors from Impact, the Short Break Delivery Partner, the NNPCF, and the Department for Education. The purpose of the meetings are to review the delivery of the programmes, consider how the delivery partners can work together, and to assist with planning for the remainder of the programmes.

The Programme Board Meets termly, and provides the opportunity for scrutiny of the delivery programmes, and for all partners to review their activity and look at the longer term and



joint learning for short breaks provision and the importance of parent participation within that to secure improved outcomes for disabled children and their families. Mary Busk, NNPCF SG rep for London currently sits, and initially Therese Lord, former NNPCF SG for the East Midlands also sat on the Programme Board. The NNPCF's role is also to act as a critical friend to the delivery partners, and where necessary to challenge progress and feedback from the forums about challenges families and forums experience and to assist with planning for the remainder of the delivery programmes.

Feedback from partners on the Board include;

“The membership of the National Network of Parent Carer Forums on the Programme Board, and the involvement of NNPCF reps has been and remains vital in ensuring there is proper scrutiny and review of the activity and work of the two programmes, and ensuring that we remain grounded about what really matters to parent carers and the issues they and Local Authorities are facing, which assist in programme planning for the future. The Programme Board would be far less effective without the input and involvement of the National Network of Parent Carer Forums.”

CDC (Council for Disabled Children) Partnership Board

The CDC Council Partnership Board is an advisory body. Their role is to support the CDC Council activity and was created following the appointment of CDC as the Strategic Partner for SEN and Disability to the DfE. Several organisations have a representative on the board and all were elected for a three year period by the CDC member organisations. The NNPCF has a rep on this group and works very closely with CDC senior management and member organisations in-between the quarterly meetings. Further details of its work can be found at <http://www.councilfordisabledchildren.org.uk/who-we-are/our-members/the-cdc-council-partnership-board>

CDC Council

The CDC Council acts as the wider stakeholder group for the CDC, bringing the whole sector together to debate key policy issues. The Council meets termly and the NNPCF have two representatives at these meetings. They are an important opportunity for the parent carer voice to be heard on a variety of issues that are important to disabled children and young people, children with SEN and their families.

More information about the CDC Council can be found at <http://www.councilfordisabledchildren.org.uk/who-we-are/our-members/the-cdc-council>

National Parent Partnership Network

We have continued to work constructively with the National Parent Partnership Network in developing stronger relationships regionally and nationally. In conjunction with local forums and Parent Partnership Services we have coproduced the Six Principles for Partnership Working which is one tool to promote the opportunities for local forums and local Parent Partnership Services to work together effectively. We have supported Contact a Family and NPPN in the planning and delivery of 'Together is Better' workshops in each region for upto 271 parent carer forum members and PPS workers. This training has been very positively reviewed and promotes closer local joint working.

Special Educational Consortium (SEC)

SEC is a group of organisations who protect and promote the rights of disabled children and children with SEN, the Group was established 25 years ago. NNPCF have a permanent place as part of both the Steering Group and the Parliamentary Group. Since the Green Paper was published we have been involved in considerable debate and clarification discussions to get a clear understanding of the proposals, as presented at each stage, for educational systems and processes. We were also consulted about the proposed last minute changes to the Education Act 2011, which enabled parents to be awarded Direct Payments for Educational provision within Pathfinder Areas. We also have a place on the sub group dedicated to Post 16 Education which considers issues related to both provision and funding.

Some of the discussions/meetings/responses/provision of evidence that we have been involved in include;

- Draft Exclusions Guidance
- School Funding Reform
- Children & YP Health Outcomes Forum
- Education Select Committee – Call for Evidence
- Children & Families Bill – Draft Provisions
- SEN Code of Practice
- Crossover between Children & Families Bill and the Care & Support Bill

We have also been active Sub Group Members working on Parental Complaints Procedures and Reform of the Primary Curriculum.

SEC is a very active and well respected Group who value our involvement as the voice of parents.

Contact a Family Health Project

Contact a Family has been funded to support the involvement of the parents of disabled children in commissioning and improving health services, through the Department of Health Innovation Fund. NNPCF steering group members have been involved in discussions around this project,

have contributed to ideas around key health topics being raised by Parent Carer Forums and have supported the dissemination of the questionnaires and opportunities for engagement that this project has generated. Much of Contact a Family's work on this has been around proving briefing papers for local PC Forums that include up to date information on the many changes that are taking place with the NHS- from both commissioning and delivery aspects, all to encourage and support Forums to seek out and engage with local health leads. These include information on who and what Clinical Commissioning Groups are and on Any Qualified Provider (AQP). Further info can be found at www.cfamily.org.uk/parentcarerparticipation

Short Breaks Network

The Short Breaks Network is a partner within IMPACT the SEND Delivery Partner for Short Breaks. They produce a Department for Education funded electronic journal called 'Better Breaks' for service providers, Commissioners, Local Authorities and families themselves about all aspects of Short Breaks. There is a multi-agency editorial team and NNPCF has a representative on this team whose role is to look at all edition planning and editorial material from a parental view point. Several of the editions cover Parent Carer Participation written by NNPCF members which look at the role that some Forums have in the commissioning, monitoring and reviewing of provision within their area. The online magazine can be accessed at <http://www.shortbreaksnetwork.org.uk/policyandpractice/betterbreaks>

James Lind Alliance (JLA) Childhood Disability Research Priority Setting Partnership

The British Academy of Childhood Disability Strategic Research Group initiated and manages the James Lind Alliance (JLA) Childhood Disability Research Priority Setting Partnership in collaboration with representatives from the James Lind Alliance, National Network for Parent Carer Forums, and Council for Disabled Children. This project engages families and clinicians to identify

and prioritise treatment uncertainties for improving the health and wellbeing of disabled children, and enables families to influence the research agenda. Mary Busk and Anna Walker are the current NNPCF representatives on this partnership.

The aim of the Childhood Disability Research Priority Setting Partnership is to identify the unanswered questions about the effectiveness of interventions for children and young people affected by neurodisability from both patient and clinical perspectives. It will then prioritise those unanswered questions that young people, parents and clinicians agree are the most important to create a 'top 10' important research topics.

“Involvement of the National Network of Parent Carer Forums is crucial to the success of the research priority setting project, by enabling the national community of families with disabled children to be aware and be actively involved in the priority setting process. Members of the NNPCF Steering Group have influenced the scope of the project, design of the website, content and style of relevant documents, and continue to be involved in directing all aspects of the work.”

Chris Morris, Senior Research Fellow in Child Health, University of Exeter Medical School

<http://www.bacdis.org.uk/research/psp.htm>

<http://www.lindalliance.org/ChildhoodDisabilityPSP.asp>

British Academy of Childhood Disability (BACD)

The NNPCF was invited to sit on the BACD in early 2012. The BACD is an affiliate group of the British Association of Community Child Health, a specialty group of the Royal College of Paediatrics and Child Health, and as the UK branch of the European Academy of Childhood Disability.

The aims of the BACD are:

- to be a means of networking and mutual support for all those working in district and tertiary level services for children with neurodevelopmental disability
- to promote communication between Child Development Teams
- to organise regular national multidisciplinary meetings on child development and disability
- to promote the development of quality standards, guidelines for good practice and audit in the field of child development and disability
- to encourage debate and promote research into the many outstanding questions in childhood disability
- to work closely with voluntary organisations and others to advocate for children with disabilities and their families

The BACD group meets three times a year and is currently chaired by Professor Gillian Baird OBE. It has representation from the disciplines of Paediatrics, Speech and language therapy, Physiotherapy, Occupational therapy, Psychology, Nursing and Education. As well as Mary Busk from the NNPCF, representatives from the Council for Disabled Children and Contact a Family also attend, along with officials from Department of Health and/or Department for Education when they have issues to discuss.

“The involvement of NNPCF has raised the parent/carer perspective to a new level providing vital insight, experience and insightful comment on all our deliberations and with others made BACD truly multidisciplinary – the only college affiliated group so constituted and it exemplifies the partnership model that is essential to make care better for disabled children and their families.”

BACD Chair, Professor Gillian Baird

<http://www.bacdis.org.uk/index.htm>

Coding Paediatric Neurodisability Outpatient Clinical Activity

A coding subgroup of the British Academy of Childhood Disability (BACD) was created towards the end of 2012 to address the lack of national and (sometimes) local data for neurodisabled children.

The group comprises Consultant Paediatricians Karen Horridge, Jane Williams, Gabriel Whitlingham and Professor Gillian Baird representing the BACD. Mary Busk from the NNPCF was invited to join to contribute to the work from a parent carer perspective.

The initial aim of the group is to develop one coding system for all neurodisability non-in-patient clinical work. This is to be used initially in pilot areas to support the national development of coding work and national and local data collection for neurodisability.

The aim is to work towards coding all paediatric neurodisability clinical work, so that we have robust data to underpin clinical practice and to inform commissioning and future research. It will also be used to inform development of the new national SNOMEDCT coding system.

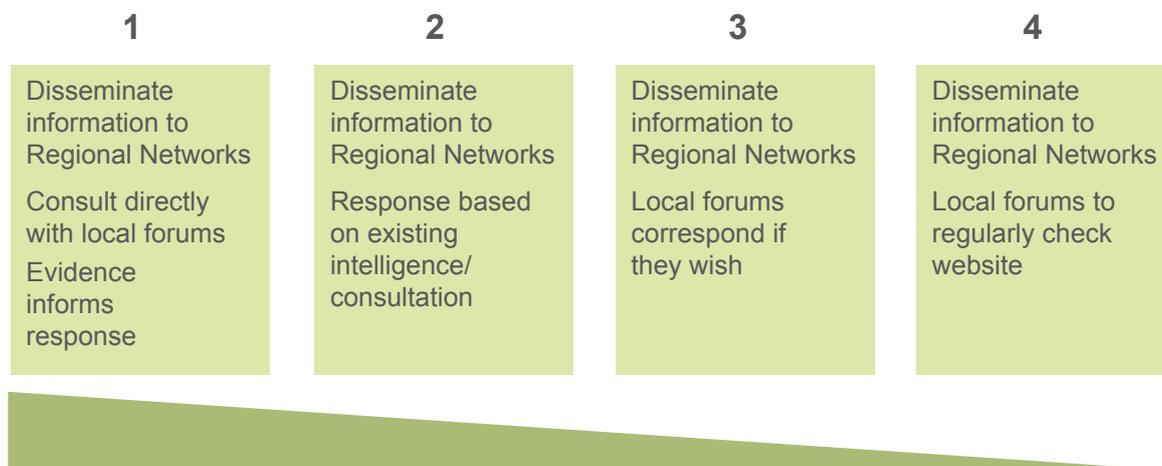
By considering carefully and testing all the aspects we want to capture, including those from the new NHS Mandate, the data analysis possibilities will be excitingly rich and should help defend and develop services for disabled children and young people. As part of this work we are also looking at how best we might collect and analyse the data nationally and locally.

Dr Karen Horridge, Consultant Paediatrician (Neurodisability), Sunderland Royal Hospital says of NNPCF involvement: “Your input to the project has been absolutely invaluable, keeping us focused, inclusive and grounded in what really matters for families. Nothing about you without you! Look forward to continuing to work closely with you and through you with the Parent Carer Forums across the UK.”

B) Responding to consultations

Some of our work and key outputs have included formal responses that are available in full on our website. These documents have either been compiled in consultation with local forums through the regular regional meetings whenever possible by collective steering group members up a short notice. We have used a decision-making tool to assist consistency and transparency in choice of different responses, see below:

Responding to National Consultations



IMPACT

The main official responses submitted include the following:

- Children and Young Peoples Health Outcomes Forum (August 2012)
- Consultation Response Form Auxiliary Aids for Children with Disabilities (December 2011)
- Response to Department for Education Green paper – Children and Young People with Special Educational Needs and Disabilities (June 2011)
- Response to Department for Works and Pensions – Disability Living Allowance Reform (February 2011)
- Response to Care Quality Commission on monitoring and improving services for disabled children and their families (February 2011)
- Response to Department for Education Green paper – Children and Young People with Special Educational Needs and Disabilities – Call for Views (October 2010)
- Response to Department of Health – Achieving

equity and excellence for children (October 2010).

All these responses can be viewed on the NNPCF website <http://www.nnpcf.org.uk/news-and-consultations>

C) Contributing to wider sector events and developments

- Speaking at conferences
- Chairing Regional events
- Attending Parliamentary events
- Attending VCS conferences

Media;

- Writing articles
- Speaking to media

Part Four: Internal development activity

Introduction

As with any organisation part of the NNPCF's focus has been on internal development and governance. This has involved developing the internal structure of the NNPCF and creating and enacting policies that define a way of working and guide NNPCF decision making. There have been some key areas for this activity, including Communications, Governance and the establishment of a Futures group, to ensure the ongoing development and sustainability of the NNPCF.

As part of our internal activity we work closely with the Department for Education, which provides the financial support for the Network. We have established a positive relationship with the government departments and a alternating attendance at our steering group meetings meet by the Department of Education and Department of Health. We regularly meet department colleagues to discuss progress and to feedback key concerns from parent carers with regard to national decision making.

Communications

Good communications are key for any group and we have prioritised the establishment of effective communication processes within the Network. Information sharing and the representation of parent carer views are a key part of our core business and it has been essential that we have processes in place to facilitate this.

The past two years have been an incredibly busy time for those involved in the world of special educational needs and disability and there has been a huge amount of information to share and many opportunities for parent carers to influence decision making. The NNPCF has facilitated the involvement of local forums in key consultations (see External Activity for further details) and provided regular updates on key issues through Communication Bulletins. We have issued regular joint bulletins with CAF and a number of more extensive NNPCF newsletters that explore some of the key issues for local forums in more detail.

We are delighted to have an upgrade of our website underway because the basic existing NNPCF website (nnpcf.org.uk) has been an important tool for our communication with local forums as well as a wider audience and we are currently developing this resource further. We have also established a presence with social media via Twitter and Facebook which supports more immediate communication with our members and partners.

Consideration has also been given to communication and information sharing between Steering Group members and NNPCF representatives. All those who attend meetings on behalf of the NNPCF are required to provide feedback to the Network, identifying key issues and information to support the delivery of a collective voice.

Governance

Establishing good governance is the responsibility of each steering group member and the whole group has worked hard to agree the key policies and procedures for this new organisation. We have been able to draw on the long and varied experience of different members and advisers, and will need to continue to consolidate governance processes we have developed, and continue to develop.

The policy documents are available on our website and include:

- Managing and supporting Reps (Draft)
- Data protection
- Code of Governance
- Code of Conduct
- Co-Chair Roles and Responsibility
- Safe Guarding
- Record of Activity
- Feedback Form
- Policy re allocation of work tasks
- Markers of good practice

- Regional Rep Selection
- Parent Representation Agreement Form
- Non Regional Rep Selection
- Reward and Recognition (organisations)
- Reward and Recognition (internal)
- Achieving Wider Representation
- Steering Group decision Making Policy
- Membership Policy
- Conflict/Duality of Interest Policy

Awaiting completion is our Equality and Diversity Policy. As our website is completed we will finalise our Communications Policy.

Now that we have defined the key aspects of our organisation we are currently working on the remaining key policy documents although some aspects of these topics are covered in the above documents. All the above work and policy development will guide our production of a Constitution (including Operational Governance and Overview) which we will produce in partnership with our regional and local forum members by the end of June 2013.

- Complaints and Grievances
- Whistleblowing
- Personal development and Disciplinary Procedures (relates to non regional post)
- Risk Register

Futures Group

The Futures Group began its life as the governance group which helped to plan and develop our governance policies and structures. It soon became clear that the two are so intricately intertwined, that it was important to consider the options for future sustainability at the same time as we developed our governance structures.

The futures group began as a smaller sub group, and met together once, and then with representatives from the Department for Education to begin some initial discussions to consider how the Department might view our position, which may assist us as we moved forward. However,



following this, we felt it was important that all members of the Steering Group were involved in the discussions.

The Steering Group held a planning day in November 2012, whereby we considered our activity, our aims, and our planning for the future, which has enabled us to think about what and how we need to prioritise over the next few months, and how we can ensure the stability, and sustainability of the NNPCF.

Recruitment and Selection

Our Key Performance Indicator for the last two years has been to establish a Recruitment and Selection process for the NNPCF. Recruitment using a transparent, criteria based approach that involves local forums has been a priority. We are pleased to report that over the past twelve months we have successfully recruited five new regional representatives who have joined the steering group. We will be undertaking two further regional representative selections over the next term, and plan to then recruit two of the non regional representative posts that will be essential to our increased capacity and activity. One of these roles will focus upon governance and one of mentoring and personal development.

Part Five: Plans for the future

We are holding a national event bringing together representatives from all the Forums on 18th March 2013. We will be discussing our members' ideas, suggestions and feedback. We will use this to develop our constitution over the summer months.

Our next steps include:

1. Preparing our Constitution
2. Consolidating our operational governance
3. Continuing to develop and embed key partnerships
4. Improving our digital and written communication resources (website redevelopment already underway)
5. Facilitating an increase in the administrative support
6. Completion of the selection process for the remaining regional representative posts, and non-regional members to the steering group.



Appendix

Here is an example of a project by one regional network:

NHS Care Pathways

The Eastern Regional Network has been involved in the co production of a generic Care Pathway for children with additional needs and disabilities. This was organised by the Strategic Health Authority (SHA) for the East and East Midlands Region. Our Representative was Mike Wilson, Chair of Family Voice Southend;

“This was an amazing journey for me, as a Parent Rep amongst up to 20 Health Professionals!!! Each Session was full of free discussion about what works and what doesn't and how Parents feel about all aspects of assessment, diagnosis, hospital consults and hospitalisation. We even talked about surroundings and how they affect children and families when they are waiting to see a consultant!!! (not popular at first.) Lots of brain storming and pooling of ideas, sometimes they were surprised at a “Parents view” but they always listened and were interested .When we came to the Launch of the results of all this to hundreds of Professionals I felt very proud of what WE had achieved and the time an energy had been well spent, who knows where it might lead...”

We have now been invited to have the same involvement in the production of Regional Care Pathways for Children with Neurodisability and Children with Asthma. We hope that other SHAs will work with NNPCF members when developing similar Pathways.



National Network of Parent Carer Forums
'Our Strength Is Our Shared Experience'



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9.30am - 5.00pm

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www.makingcontact.org