



National Network of Parent Carer Forums

'Our Strength is our Shared Experience'

NNPCF & Contact a Family Parent Carer Participation Bulletin January/February 2012

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contact a family
for families with disabled children

Strengthening Parent Carer Participation

The Strengthening Parent Participation Programme kicks off the New Year with a new communications strategy. To ensure contact with local forums is well co-ordinated the National Network of Parent Carer Forums and Contact a Family will be issuing regular joint 'Parent Carer Participation' bulletins. These will have key updates about the support programme and national information. They will be supplemented by NNPCF newsletters in the spring, summer and autumn which will provide more in-depth information about the work of the NNPCF and guidance on how forums might tackle issues in their local areas. They will also enable forums to promote their activities and share good practice. We would appreciate feedback to ensure the bulletins and newsletters provide you with the information you need.

Participation Grant Update for 2011-12

Forums wishing to claim the remaining £2,500 grant from the DfE should put in their applications ASAP. You should have received a simple form to fill in but please contact your Regional Advisor if you have any questions about doing this. The final date for submitting an application is March 8th as we need to process the payment. You do not have to apply for the full amount and can apply for any amount up to the £2,500 (or less for forums with an underspend last year). Please do consider applying but only if you are sure you will spend it before March 31st. Please alert your Regional Advisor if you would like to make any major changes to your workplan or budget outlined on your original grant application.

New Grant Process for 2012-13

The Department for Education and Contact a Family fully appreciate how difficult the grant administration process was for forums last year, and the immense challenges it placed on them and the decreased participation activity that some forums experienced as a result of the delay. There has been a commitment to trying to review and revise the process to minimize the gaps that forums have where they have potentially no income, or their grant application is being processed. We know forums appreciate that there are legal and auditing requirements that have to be applied to a central government grant, even when it is for such a small amount, and some changes to those requirements caused some of the particular difficulties this year. As such, we have been working hard to try to find a system that will work better for forums but still meet these legal and auditing requirements.

Contact a Family had hoped to be able to provide information via this newsletter confirming the details of this, but are still waiting for the final approval. As such, we anticipate that Contact a Family will send a further communication to all forums next week explaining how this will work, and hope to make available both the monitoring forms for the 2011-12 grant, and the application form for the 2012-13 grant before the end of February.

We know that many forums have already asked for details of these, so please watch out for the email next week and contact Kate Johnstone the Grants Programme Officer (Kate.Johnstone@cafamily.org.uk) if you have any other queries.

Important Information for Forums

New Department for Education Delivery Partners

A Delivery Partner is an organisation that the Department for Education have contracted to work with local areas / forums / parent partnership services in relation to a specific issue (e.g. short breaks / transition / parent forums). More information can be found below. It is worth checking them out as most will be working in your local area, or with your local authority in some way, and may be able to assist you with elements of your forum work. More information about the Green Paper delivery partners can be found using the links listed below.

The Bond Consortium: child mental health

The Early Language Consortium: early language development

The ES Trust with the National Children's Bureau: early support and key working

Contact a Family and the National Network of Parent Carer Forums (NNPCF): parent carer participation

The National Parent Partnership Network: supporting Parent Partnership Services

The National Development Team for Inclusion the Council for Disabled Children and Helen Sanderson Associates: preparing for adulthood

The IMPACT consortium: short breaks delivery

EDCM Report Published - Short Breaks Services Statements: Commitment and Transparency

In October EDCM wrote to all local authorities (LAs) in England asking to view their short breaks services statements which LAs were required to publish by 1st October 2011 under the Breaks for Carer of Disabled Children Regulations 2011 or the 'Short Break Duty'. They received 55 short break statements and have looked at these statements against the requirements in the Short Break Duty. The findings are published in the new EDCM report 'Short Breaks Services Statements: Commitment and Transparency'.

EDCM is currently calling for the Government to collect evidence on the impact of the Short Break Duty on the ground. The Campaign is concerned that in the context of non-ring-fenced funding and the closure of many disabled children's services that success in delivering requirements under the Duty may be masking a reduction in short breaks for disabled children.

EDCM are requesting the help of all local parent carer forums in finding out how the Short Break Duty is working locally. They have produced a number of questions about the experience of the Short break Duty for local forums to consider.

Further information on this work and a list of the questions are on the NNPCF website <http://www.nnpf.org.uk/news-and-consultations>

Green Paper Pathfinders

20 pathfinders covering 31 local authorities and their Primary Care Trusts (PCT) and emerging Clinical Commissioning Group partners were selected by the Department for Education to trial various different elements of the Green Paper proposals. In addition, the Department has announced the appointments of SQW to evaluate the pathfinder programme. NNPCF Steering Group representatives are working with SQW. For details of areas; <http://www.education.gov.uk/childrenandyoungpeople/sen/b00191706/send-green-paper-pathfinders>

SEND Green Paper Pathfinder Website Launched

Mott MacDonald, as a supporting organisation to each of the Pathfinders, has launched the 'SEND Pathfinder' website. This website will be available for anyone to access for information on the activities during the Pathfinder project. The site has several different elements and gives information on a number of the organisations and local authorities involved in the project. It will be updated regularly with information about activities and presentations from Pathfinder and national events. www.sendpathfinder.co.uk. For more information on the pathfinder site and pathfinder project email pathfinder@mottmac.com.

Pathfinder Area SE7 Launches Website

The largest pathfinder area South East 7 which covers seven Local Authorities has launched its own website. The site provides information about who is involved in the project and how they can be contacted and as the pilot progresses details of the work being carried out. For more information visit <http://www.se7pathfinder.co.uk/home-1>

Council for Disabled Children Winter Digest

The Digest includes an introduction by the Minister, Sarah Teather and her response to commonly asked questions about the Green Paper. For the latest issue of the CDC Digest www.councilfordisabledchildren.org.uk/media/160978/cdc_digest_winter_2011.pdf

Updates about Health

Any Qualified Provider (AQP)

Continence and Wheelchair Services are likely to be the two main areas of interest in Phase 1 for parent /carers and the Continence Contract Specifications and guidance pack has been published. The Wheelchair specifications and guidance is still under discussion. Representatives from all PCT's who have selected Wheelchair Services, as part of the AQP process have been invited to a meeting on the 31st January to discuss this services and how AQP might impact on it. AQP offers a good opportunity for local forums to make contact with Clinical Commissioning Groups and Local 'LINKs' to ensure that the parent carer voice is heard and to make sure services provided for disabled children meet their needs. All PCT clusters have now selected the services that locally are to be considered for the AQP process. Information about these selections and further details are available on the AQP Resource Centre website at <http://www.supply2health.nhs.uk/AQPResourceCentre/Pages/AQPHome.aspx>

Resources to support forums in discussions about these services can be found at www.cafamily.org.uk/families/parentparticipation/nhsparentcarerparticipation/nhs.html

NHS Parent Carer Participation

Parent carer forums will need to build relationships with the new organisations being set up to replace the Primary Care Trusts when they cease to exist. A hand-out giving more detail about this – including who to contact and what questions to ask is on the NHS Changes section of Contact a Family's website. www.cafamily.org.uk/families/parentparticipation/nhsparentcarerparticipation/nhs.html

Children and Young People's equivalent to the NHS Future Forum

Christine Lenehan, Director of CDC has agreed to co-chair a new Children's and Young People's Forum. The Forum, launched on Thursday 26th January by the Secretary of State for Health, will operate as an equivalent to the NHS Future Forum 'listening exercise' for children and young people. It has been tasked with creating a Children's and Young People's outcomes strategy which will focus the health service on improving health results for children, including those needing primary, hospital and urgent care, and children with long-term conditions and addressing longstanding system issues that prevent children from accessing universal and specialist healthcare. It will also ensure that children's health needs are central to government thinking during the final phase of development work on Health & Social Care Bill reforms. To inform the strategy, a group of independent experts from local government, the NHS, charities and parent carer representatives will hear the views of children, parents, carers and wider families as well as health professionals.

Support for Forums from Contact a Family

Advisors and Associate support

Contact a Family's new team of Regional Advisors are working with parent carer forums throughout England helping them access support and learning opportunities. In addition a team of Associates have been recruited to provide intensive one-to-one support to forums facing the biggest challenges. These workers are experienced in areas such as managing conflict within groups, developing forums and working with local authorities. Many of these are parent carers themselves.

Forum2Forum

Contact a Family's commitment to peer-led support is being developed in its new Forum2Forum programme. This will give forums the opportunity to share learning and expertise with each other and will reward and remunerate those who can deliver the level of support required to other forums. It will also create opportunities for those involved in participation in their own area to gain wider experience by working with other areas. We hope this will continue to build resilience and self sustainability into parent participation. Contact a Family will also develop its website and social media as a means of sharing good practice.

Learning Opportunities

You can now find a list of recommended training providers on the Contact a Family website at <http://www.cafamily.org.uk/families/parentparticipation/e-newsletter.html>. This will help forums source the training they need and share details of trainers who have a proven record of supporting forums. Contact a Family will also be organising regional training for forum members on the subjects which forums have identified as most important. These will include The Law, Disabled Children and Parent Carer Forums; Managing Difficult Situations; Legalities of Forums (e.g. governance) and Working with Local Authorities and Health Providers. Please do tell us of trainers you would recommend to other forums. Contact a Family will also be working with other partners to organise regional training events.

Please contact your local regional Advisor for support and information;

- Carolyn Deveney - North West carolyn.deveney@cafamily.org.uk 07905 917 066
- Cheryl Elliott- Midlands & East of England cheryl.elliott@cafamily.org.uk 01332 557 975
- Heather Tarbuck - London heather.tarbuck@cafamily.org.uk 020 7608 8744
- Laura Burling - NE and Yorks & Humber laura.burling@cafamily.org.uk 01625 537 342
- Sue Mennear - SW and SE sue.mennear@cafamily.org.uk 0117 9512 387

For more information about support and learning opportunities visit www.cafamily.org.uk/families/parentparticipation/index.html and <http://www.cafamily.org.uk/families/parentparticipation/e-newsletter.html>

Updates from the National Network of Parent Carer Forums

The NNPCF Steering Group, and other parent carers who have been willing to represent the NNPCF have continued to be extremely active and have attended many national events to promote the work and value of parent carer forums. Full details will be provided in the full communication from the NNPCF in the spring.

Regional Selection Processes

As you will be aware, the NNPCF have moved to a new selection process for the Steering Group Representatives and will be undertaking this new process across the 9 regions over the next 18 months. The first three regions who will select their Steering Group representative are: West Midlands February 2012; North West February 2012; Yorkshire & Humber March 2012. For details about the selection process, and how individuals can submit expressions of interest, please go to www.nnpcf.org.uk. Watch this space for details of the outcome!

Opportunities to engage

Personal Independence Payment: assessment thresholds and consultation

The Personal Independence Payment (PIP) will replace Disability Living Allowance (DLA) from 2013. As part of this transition the government has been looking at changing the assessment criteria for PIP. Ministers have said that without reform, there would be 2.2

million people on DLA by 2015–16, but with the introduction of PIP, this figure falls to 1.7 million. The transition to PIP was confirmed, on 17th January, when the House of Lords rejected an amendment to the Welfare Reform Bill, which would have delayed the replacement of the DLA. Peers voted by 229 to 213, to reject an amendment tabled by Paralympian Lady Grey-Thompson. She proposed holding pilots of the new benefit before implementing it fully, but the government warned her plan would cost £1.4 billion. There are concerns that the move to PIP could result in half a million disabled people being no longer eligible for benefit (<http://www.mencap.org.uk/news/article/half-million-disabled-people-may-lose-benefit>). The PIP consultation opened on 16th January and runs until 30th April. For further details visit <http://www.dwp.gov.uk/consultations/2012/pip.shtml>.

The Office for Disability Equality (ODI)

The office for disability issues has launched a consultation on the government strategy on disability equality. IT sets out areas for discussion based on three key principles: Realising aspirations, Individual Control and Changing attitudes and behaviors. Responses to the consultation document will feed directly in to the government strategy, which will be published in spring 2013. Closing date is Friday 9th March. <http://odi.dwp.gov.uk/odi-projects/fulfilling-potential.php>

Include Me Too

Include Me Too are undertaking work looking at the involvement and participation of Black and Minority Ethnic Parent Carers in forums. They would be grateful if forums would consider completing their questionnaire which can be found at <http://www.nnpcf.org.uk/news-and-consultations>. The closing date for this is Friday 2nd March 2012.

Contact a Family

Contact a Family's current strategy 'Putting Families First' comes to an end during 2012. They are looking to the future and at how Contact a Family can best make a difference with and for families with disabled children in the coming years. CAF would be grateful if parent carers would answer a short questionnaire to ensure they focus their work in the activities that make the biggest differences to families. Closing date for this Friday 2nd March. <https://www.surveymonkey.com/s/ContactaFamilystrategy2012-15>

STOP PRESS...All Party Parliamentary Group on Autism launches SEN commission. To get involved see details at <http://www.appga.org.uk/news-and-reports.aspx>

The NNPCF Steering Group is currently producing the next newsletter which will include further information about many of the topics highlighted above. If you have any questions, topics or information that you would like covered, please contact the NNPCF via Sue North on 07738 896474 or sue.north@cafamily.org.uk.

www.nnpcf.org.uk

www.cafamily.org.uk/families/parentparticipation/