

# NNPCF & Contact a Family

## Parent Carer Participation Bulletin

### May 2012 No 3

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National Network of Parent Carer Forums

'Our Strength is our Shared Experience'

**contact a family**  
for families with disabled children

Strengthening Parent Carer Participation

## CHILDREN AND FAMILIES BILL TO GIVE FAMILIES SUPPORT WHEN THEY NEED IT MOST - NEXT STEPS

The Government has just announced that it will overhaul the Special Educational Needs (SEN) system and reduce delays in the family justice and adoption systems, under new legislation announced in the Queen's Speech on 9 May.

The planned Children and Families Bill will deliver better support for families – legislating to break down barriers, bureaucracy and delays which stop vulnerable children getting the provision and help they need. The Bill is expected to be introduced early in 2013.

The key measures relating to SEN will be:

- replacing SEN statements and Learning Difficulty Assessments (for 16-25 year olds) with a single, simpler 0-25 assessment process and Education, Health and Care Plan from 2014.
- providing statutory protections comparable to those currently associated with a statement of SEN to up to 25 in further education – instead of it being cut off at 16.
- requiring local authorities to publish a local offer showing the support available to disabled children and young people and those with SEN, and their families.
- giving parents or young people with Education, Health and Care Plans the right to a personal budget for their support.
- introducing mediation for disputes and trialling giving children the right to appeal if they are unhappy with their support.

The legislation would draw on evidence from 20 local pathfinders set up in September 2011. The interim evaluation reports are due in summer and late autumn 2012, with a final report in 2013.

Ministers have committed to making all the necessary legal changes needed to put in place reforms proposed in the *Support and Aspiration* Green Paper. The Green Paper was published for consultation in March 2011 – and Ministers have now also set out their detailed response and reform timetable.

'Support and aspiration: A new approach to SEN and disability - progress and next steps' was published on 15th May <http://www.education.gov.uk/childrenandyoungpeople/sen/a0075339/sengreenpaper>

## Parent Carer Participation Event on March 28th in Birmingham

The National Parent Carer Participation Event on the 28<sup>th</sup> March, where we focused on the Health Outcomes Forum was well attended, and received excellent feedback. You can download the powerpoint presentations on the NNPCF and CaF websites, and shortly there will be video footage of each of the presentations and an overview film also on the websites.

## Parent Carer Participation Grants 2012/13

Remember that you can apply for your parent carer participation grant **NOW** – you do not need to wait for your grant monitoring to be submitted or approved. Please remember that the application process can take 4-6 weeks, so if you can factor this in to your planning. The application forms are available on <http://www.cafamily.org.uk/families/parentparticipation/supportparentforums.html> If you have any queries, please contact your Regional Advisor, or Kate Johnstone, the Grants Programme Officer on 020 7608 8783.

## 2011/12 Grant Monitoring Forms

The 2011/12 Grant Monitoring Forms should have been completed and returned to Contact a Family. However, we are still waiting for some of these, so please complete and return as soon as you can, or speak to your regional advisor if you are experiencing difficulties with this. Please remember we will be unable to process the second part of your 2012/13 grant payment until we have reviewed and approved your grant monitoring form.

## Learning and Development Opportunities

You should have received information about the learning and development opportunities in your region from Helen Jones, Programme Office at Contact a Family. You will remember that regions identified their top requirements for learning and development opportunities, and this is what we are now delivering across England. Please look at the dates for your area, and make sure you use your place. Any member of your forum can attend these opportunities, it does not need to be a steering group member. For details about the dates and venues please go to

<http://www.cafamily.org.uk/pdfs/Table%20of%20Training%20by%20Region.pdf>

*“Lots of really useful information and advice. Would definitely recommend the training”*

*Forum member*

## Improving access to health services for families of disabled children

Two new case studies have been added to the web, describing how parent carer forums worked with hospital staff to improve the experience for disabled children visiting hospitals in Cambridge and Bristol. [www.cafamily.org.uk/families/parentparticipationhealthservices.html](http://www.cafamily.org.uk/families/parentparticipationhealthservices.html)



## Wheelchair and continence services

Some parent carer forums are now working with commissioners developing continence and / or wheelchair services to be provided by Any Qualified Provider (AQP). It will be harder for forums to influence these services once AQP contracts have been agreed. If you are involved in this work or struggling to find who to link to in health please contact Sheila Davies at [Sheila.Davies@cafamily.org.uk](mailto:Sheila.Davies@cafamily.org.uk).



Richard Sutton—Y&H  
Sherann Hillman—NW



## Welcome to new regional representatives on the NNPCF Steering Group

Over the last four months, we have been recruiting to the Steering Group roles, and are delighted to welcome Sherann Hillman as the new representative for the North West, and Richard Sutton for Yorkshire & Humber. Sarah Thomas was also re-selected for the West Midlands. We will be undertaking the selection process in other regions, and for the non regional representative roles over the coming 18 months. We are also looking for non steering group representatives who are interested in representing parent carers and the National Network at national meetings and events. If you are interested in this, then please look go to [www.nnpcf.org.uk](http://www.nnpcf.org.uk) and look at our governance documents "Achieving Wider Representation".

## Other activity the NNPCF have been involved in

Meeting regularly with the Department for Education  
National Advisory Group  
Pathfinder Advisory Group  
Council for Disabled Children  
Special Educational Consortium  
Family Fund Review  
Every Disabled Child Matters  
Working with CaF Parent Participation and Health Project  
Working with SQW for Pathfinder Evaluation  
Linking with all of the SEND Delivery Partners (Parent Partnership, Early Support, Short Breaks, Preparing for Adulthood, Achievement for All)  
National Link Group

The NNPCF will shortly be producing a longer communication with more details about what we have been involved in to represent parent carers and forums.

## Opportunity for parent carer to work with the Early Support Consortium

Early Support are looking for a Parental Involvement Co-ordinator to help deliver the Early Support Programme. They would be keen to hear from parent carers who are active members of a parent carer forum. Although the role is primarily to offer support in the South, applicants from interested individuals from any part of the country who meet the role description and who would be able to travel would be welcomed. For more details about the role, including the role description, and details about salary are available by going to <http://www.nnpcf.org.uk/news-and-consultations>

If you are interested in this position, want please submit a CV and letter of interest, or if you want to find out more, contact Kim Bevan, Early Support Director, Mobile 07870585652 Home office 0292 051 3010 or email [Kim@estrust.org.uk](mailto:Kim@estrust.org.uk)

# Opportunities to participate

## The Children's Outcome Measurement Study (CHUMS)



We are looking for parents of disabled children who want to take part in an exciting research study to help develop a Patient Reported Outcome Measure (PROM) for disabled children.

As part of an important new health study the Council for Disabled Children would like to speak to parents of children and young people with neurodisabilities about their health, what health outcomes are important to them and how the NHS can measure them.

This is a vitally important opportunity for parents to have their say about health care. If you work with parents or are part of a parent forum and know parents who would be interested in taking part in this study we would like to hear from you. We are looking to run 6 (one off) focus groups across the country with up to 12 participants in each focus group. If you are interested please contact Amanda Allard at [aallard@ncb.org.uk](mailto:aallard@ncb.org.uk) or on 020 7833 6843.

### Survey: Caring and Paid Work

Working Families has launched a survey to find out more about the barriers facing parents /carers of disabled children who want to work. We know that childcare and negotiating flexible working are major challenges and we also know that parents who give up work find it extremely difficult to get back into the labour market. But if we are to provide targeted support and campaign for change we need to know much more about the barriers facing parents and carers who want to combine caring and paid work. If you have a disabled child under 25 please complete our survey online by going to <http://www.surveygizmo.co.uk/s3/775921/Working-Families-2012-Survey> Postage paid hard copies can be obtained by contacting [janet.mearns@workingfamilies.org.uk](mailto:janet.mearns@workingfamilies.org.uk)

### Family Fund Review

Family Fund want to make sure they do the best they can for families. That is why they really want to hear your views about how grants and the services they provide make a real difference. If you have a few minutes to spare please complete a survey by going to <http://www.familyfund.org.uk/get-involved/help-us-with-a-survey>

### Regional Network Meetings

Don't forget to find out when your next regional network meeting is. These are really important opportunities for forums to meet together, share intelligence and information, and have the opportunity to support and gain support from other parent carer forums. If you want to know when and where your next regional network meeting is, contact your NNPCF regional representative, or your CaF Regional Advisor.

**Watch out for information coming soon about Joint Regional Events in your area**

If you have any questions or queries about the above, please contact your Regional Contact details are available on the Contact a Family website or [please click here](#).

**The NNPCF Steering Group is currently producing their next communication 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](mailto:sue.north@cafamily.org.uk). or [www.nnpcf.org.uk](http://www.nnpcf.org.uk)**