

# December 2011 Communication Bulletin



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

The NNPCF Steering Group, and members have been extremely active over the last few months. We all know how time is precious, so we thought we would provide a brief update of the different things where we have ensured that our parent carer voice has been heard.

## **Motability – changes to Insurance**

EDCM alerted us to proposed changes to the Motability Scheme that will mean that for new customers from the 1<sup>st</sup> January drivers will have to live within 5 miles of the disabled person to be ensured on the motability car. We were very concerned about the impact that this would have on families with a child living in residential school, children with parents living more than 5 miles apart, where short break staff are currently insured on the car and where other relatives, or personal assistants living away from the family provide significant care.

EDCM and wider members of the NNPCF, Mary Busk, Richard Sutton and Diane Jackson met with Motability's Chief Executive on the 15<sup>th</sup> November and he made reassuring comments that the above were unintended consequences of the new policy and that they would look into mitigating the impact of the policy in those circumstances. We expect a full response from Motability on either the w/c 12<sup>th</sup> or 18<sup>th</sup> December. EDCM will circulate details of their response. Please check the NNPCF website for this over the coming weeks.

## **Response to Auxiliary Aids Consultation**

Based on our guidelines about responding to consultations, we determined that the NNPCF should provide a response to the Auxiliary Aids Consultation, but that it would be a level two response whereby the Steering Group responded, and where possible asked local forums to consider responding and copying us in to their responses. This was completed by the deadline. You can see our response on our website

[Consultation Response Form Auxiliary Aids for Children with Disabilities](#)

### **Working with National Parent Partnership Network**

We are aware that there are many ways in which working with Parent Partnership Services can be extremely helpful, but are also aware of some tensions that exist in some areas between parent partnership services and parent carer forums. As such, the Steering Group met with Daisy Russell, the National Lead for the NPPN, and have agreed a way forward to consider some best practice guidance for parent partnership and parent carer forums to work together to provide the best outcomes together.

### **Work with SEN Green Paper Pathfinders**

The Department for Education invited the NNPCF to present at an event for Green Paper pathfinders.

<http://www.councilfordisabledchildren.org.uk/what-we-do/strategic-partner-work/sen-and-disability-marketplace-resources>

Carrie Britton was able to attend a present information about the essential requirement for pathfinders to ensure that their parent carer forums were meaningfully engaged with them from the start of their planning, and produced a document entitled “markers of best practice” for parent participation which was circulated to pathfinders. You may have received a copy of this in your regional meetings, or if not you can find it on our website.

[NNPCF Final Markers of good practice in Parent Participation](#)

### **Work with Council for Disabled Children**

The NNPCF have now been elected on to the Council for Disabled Children, and two Steering Group members, Sarah Thomas and Anna Gill share this work. We are pleased to be members of the Council as it enables us to ensure that other members remain up to date and aware of the developments in parent participation, as well as ensuring that we remain fully updated and aware of what is happening nationally.

<http://www.councilfordisabledchildren.org.uk/who-we-are/our-members/the-cdc-council-partnership-board>

### **Raising the profile of Parent Carer Participation**

The NNPCF were invited to speak at the Dyslexia and SPLD Conference. Sarah Thomas and Therese Lord were able to attend and promote the participation of parent carers to the many attendees

### **Work with other DfE Contracted Partners and Grant Holders**

The Department for Education have also commissioned organisations to support the Short Break Programme, Transition, Early Support, Parent Partnership, and an organisation to support the Pathfinder work, and an organisation to evaluate the Pathfinder work. The Council for Disabled Children are the Department for Education's strategic partner. You can find details of all of these providers on the Council for Disabled Children website [www.councilfordisabledchildren.org.uk](http://www.councilfordisabledchildren.org.uk).

The Council for Disabled Children, the DfE and the DoH held a day on the 7<sup>th</sup> November to enable these partners, and organisations who have been given national grants to meet and network. The NNPCF along with Contact a Family facilitated a session where they were invited to facilitate a session about parent participation and meet with these various organisations.

Following the announcement of the contracts, the NNPCF have made links with Parent Partnership, Short Breaks, Early Support, Pathfinder support and Pathfinder evaluation to consider how parents are actively involved with all of these delivery strands and ensure that parent participation lies at the heart of all of this work.

### **Work with the Special Education Consortium**

The NNPCF are also now members of the Special Education Consortium and Karen Wooddissee and Johanna Smith are the representatives who attend the various groups, including the Parliamentary Group. This has enabled us to be involved with and comment on a range of developments that happen often and quickly within this arena.

<http://www.councilfordisabledchildren.org.uk/what-we-do/networks-campaigning/special-educational-consortium>

### **Involvement with the Department for Works and Pensions**

The NNPCF had been invited to sit on the implementation panel for the new Personal Independence Payment, and having attended the first meeting, it was made clear that being involved was purely to be part of the delivery, rather than being able to input into any element of decision making about the PIP. As such, we decided that this would not be a priority area for us, although we have remained “in the loop”, and attend where we think it may be particularly useful. Mary Busk attended on behalf of the NNPCF and we will remain involved where we think the issues to be discussed are pertinent to disabled children and parent carers.

### **Links with the Department of Health**

The NNPCF Steering Group are pleased that we now have regular links with the Department of Health with officers now attending Steering Group Meetings on a bi monthly basis. Following the first attendance, the NNPCF were linked with AQP, and now feel that we have a clear strategic link.

### **Links with the Department for Education**

The NNPCF Steering Group continue to meet bi monthly with the officer from the Department for Education responsible for Parent Participation. You will recall that many of our discussions with him have been about the issues raised by local and regional forums in relation to the late payment of the grant, and the huge impact this has had. Having a clear and direct regular link to both officers is a huge step forward, and provides the opportunity for local and regional forums to ensure that their issues are raised at that level, so please ensure that you use your regional representative to do this.

### **Meeting re Any Qualified Provider**

Following our meeting with the DoH we were linked with the AQP section and were able to comment on the AQP draft guidance re continence. Anna Gill and Karen Wooddissee subsequently attended a wider AQP meeting and further details of this work area will be provided in the next NNPCF newsletter. For further info see: <http://healthandcare.dh.gov.uk/aqp-answers/>

### **Work on the EDCM Tadworth Disabled Children and Health Project**

Ruth Card and Mary Busk worked with a project board to develop a national paper in relation to Health. Mary presented about the parental experience at a national conference that launched this paper. You can read the full document by going to <http://www.edcm.org.uk/resources.aspx>

### **Meeting with Sarah Teather**

A number of members from the Steering Group were invited to meet with Sarah Teather on 15<sup>th</sup> November along with other parent carers. Some of the key issues discussed included the concerns about the

- General confusion about SEN pathfinder work, clear communication lacking
- There is a real belief, even though it may be unfounded, that the government want to undermine the legal protections for SEN in the Education system
- There is concern that cuts at a local level and confusions about the future roles of health and schools are leading to poorer services for disabled children and their families whatever central governments intent might be.
- Concerns that at that point the Parent Participation Grants had still not all been paid

She listened attentively to all of our views, and provided assurances that the current statutory duties in relation to SEN and statements remain, and that although there are areas who are “pathfinding” this does not exempt them from these duties.

### **Draft Resources for training teachers in SEN**

Lamb Resources Project Voluntary Organisations’ Event

Ruth Card attended this event at the Institute of Education on Tuesday November 15th, which gave feedback on the draft materials for advanced training modules for teachers in mainstream schools in five areas of special educational needs (SEN).

**Articles for the Short Break Network Best Practice Journal**

Members of the Steering Group were asked to contribute towards the Short Break Network Best Practice Journal. You can read the articles by going to this website

[www.shortbreaksnetwork.org.uk](http://www.shortbreaksnetwork.org.uk)

The NNPCF Steering Group wish you and your families a very happy Christmas and look forward to continue working with you all in 2012.

A further joint communication bulletin with CAF will be circulated in January 2012, followed by a NNPCF Newsletter being issued in February, providing more detailed information.

