

INFORMATION BULLETIN

September 2011



National Network of Parent Carer Forums

'Our Strength is our Shared Experience'

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PARTICIPATION GRANT UPDATE

Dear Parent Carer Forums,

We hope that you all received the letters that were sent from Contact a Family when it was confirmed that we had been successfully contracted by the Department for Education (DfE) to continue to support the development of parent carer participation and to administer the grants.

We know that the speedy processing of the grants is a top priority for forums, and in the last few weeks we have been working extremely hard to process as many of the application forms as we can. You may have been contacted by a member of the team asking for clarification about elements of your plan, or if you were missing signatures from your form.

When we review your application, we have to consider information from last year, including how well last year's grant was spent, if there was an underspend and ensure that the current application meets the conditions of grant. Once we are satisfied that it does, we make a recommendation to the Department for Education that your grant application should be approved.

The form is then sent to the DfE for them to review and process for payment.

Currently we have forwarded 40 grants to the DfE, and by the end of this week hope to have forwarded over two thirds of the applications. If we do contact you to clarify information, or to seek missing signatures or because we feel we need to meet with you to discuss your application, the quicker you are able to respond, the more speedily we will be able to process your grant.

Both the Department for Education and Contact a Family realise how difficult it is currently for forums to undertake activity until you receive your grants, and that it has now been a considerable period of time since the end of the last grant. The reasons for this delay were not things that we had any control over, and we are committed to ensuring that the process next year runs smoothly and as timely as possible.

Sue North,

Director of Operations, Strengthening Parent Carer Participation, Contact a Family

New Contact a Family survey – 'Isolation 2011'

Families sometimes report that they feel isolated and alone. There may be other reasons or situations when families with disabled children are affected by isolation which can impact on all areas of life.

Contact a Family wants to find out what the situation is for you and your family and if isolation impacts on your family life.

The survey will take just five minutes to complete and the findings will help us highlight this issue through a media story. We are inviting responses until **23rd September** and the survey is available on this link: <http://www.surveymonkey.com/s/ContactaFamilyIsolation2011>



ACT Big Study for Life-limited Children and their Families

The Big Study for Life-limited Children and their Families (The Big Study) is a research project, based in the West Midlands and led by UK children's palliative care charity ACT. Funded by Big Lottery Fund, this is the first in-depth study in the UK to examine how well the needs of children with life-limiting conditions and their families are being met.

The study will determine and map those services that are currently used by children with life-limiting and life-threatening conditions, identify and document children's and families' needs, and explore gaps in service provision and the accessibility of services to those who need them.

For more information about The Big Study for Life-limited Children and their Families, please contact ACT - Telephone 0117 916 6424 or email info@act.org.uk

Low Review

The Low Review, which is being led by Lord Low of Dalston, is looking into how the mobility needs of people living in residential care are met and funded. The Low Review will make recommendations on the funding and responsibility for personal mobility in state funded residential care.

In August 2011, the review issued a call for evidence, inviting anyone with an interest, particularly those living in state funded residential care, care home providers and local authorities, to share their views and insights on how personal mobility needs are met for people living in residential care.

For further details, please contact 0203 242 0373 or email info@lowreview.org.uk. Responses can be left on their website at www.lowreview.org.uk and go to 'Call for Evidence'.

The closing date for responses is midnight 10 October 2011

KIDS and Mencap Holiday Childcare Survey

KIDS, in partnership with Mencap have developed a survey for parents and carers of disabled children and young people, to find out about their access to holiday childcare this summer.

Some parents have contacted both KIDS and Mencap over the summer holidays to talk about difficulties they have had accessing childcare for their disabled children. This is not OK! The survey will help to find out what the picture is nationally for families with disabled children and young people in relation to their access to holiday play and childcare provision.

The survey contains a maximum of 25 questions, should take 5 -10 minutes to complete and can be accessed via the following methods:

Web link: <http://www.surveymonkey.com/s/2011summerchildcare>

Paper survey that can be sent in the post.

Telephone interview. Please call 0207 359 3073 and ask to speak to Anna Route.

Please complete the survey by **October 7th**



NHS and Any Qualified Provider

The Department of Health is committed to extending patients' choice of Any Qualified Provider. This means that when patients are referred for a particular service, they can choose, where appropriate, from a range of providers that are qualified to provide safe, high quality care and treatment, and select the one that best meets their needs. Initially the focus will be on a small number of the services where patients have said in response to the earlier consultation on proposals that they want more choice. These services are:

- Services for back and neck pain
- Adult Hearing Services in the community
- Contenance Services (adults and children)
- Direct Access Diagnostic tests
- Wheelchair services (children)
- Leg ulcer and wound healing
- Podiatry services
- Primary Care Psychological Therapies (adults) ('talking therapies')

By the **30th of September** PCT clusters have been asked to consult with individuals who use the above services, to identify which of these services above should be priorities for the implementation of the new guidelines that extend patient choice.

See <http://healthandcare.dh.gov.uk/any-qualified-provider> for more information.

EDCM in association with Irwin Mitchell Solicitors launched a template letter to help families with disabled children to gain an assessment for social care services

Lots of families with disabled children report that they have struggled to get an assessment from their Local Authority. Under the law, councils must assess every child who is or may be a child 'in need'. Children are 'in need' if they are 'disabled'. Therefore, it is unlawful for a local authority to refuse an assessment for a disabled child.

This template letter is intended to help parents who have been told that their council will not assess their disabled child in relation to short breaks or any other specialist social care service.

The first step for a parent of a disabled child who needs short breaks, or other social care services, is to ask for an assessment. Parents should ask their social worker (if they have one) or the duty worker for the Disabled Children's Team (or equivalent) if they will carry out the assessment. If the answer to a request for an assessment is 'no', then a version of this letter can be sent to explain the legal situation.

For further details see http://www.ncb.org.uk/edcm/assessment_letter.pdf

Invitation to Join the SEC Policy Network

The Special Educational Consortium (SEC) is a coalition of voluntary and professional organisations working to ensure Government policy reflects the interests of disabled children and children with SEN. SEC has excellent access to ministers and civil servants at the Department for Education and is highly respected by Parliamentarians of all parties. This is your opportunity to join SEC's policy network and help shape Government policy on special educational needs (SEN). Join SEC's policy network and you will get:

- briefings on key developments in special educational needs policy from our specialist staff;
- invitations to attend workshops and seminars; and
- the chance to inform what we say to Government.

Membership is open to all individuals and organisations who share our commitment to disabled children and children with special educational needs and is absolutely FREE. Visit our website to fill in the short application form and join today. http://www.ncb.org.uk/cdc/networks/special_educational_consortium/about_us/sec_policy_network.aspx