

In Touch



Contact a Family - Northern Ireland Bi Monthly newsletter
December 2010

The staff at Contact a Family, N Ireland, would like to take this opportunity to wish you all a very Happy Christmas and a peaceful and prosperous New Year. We thank you for all your support and assistance throughout 2010, and look forward to our continued partnerships and working together to improve the lives of families of children with disabilities in 2011 and beyond.

Contents

Campaign news

Stop the DLA Takeaway update
Fuel poverty and disabled kids
Christmas carol downloads
New Service For Congenital Heart Disease Launched
Special educational needs - A Guide for Parents
Lone parents - changes to Income Support
Lady Allen of Hurtwood Trust - Travel Awards

Training

'Made of Money' - a 2 day 'train-the-trainer' course
Grandparents matter? Invitation to attend a seminar
NAS - family support programmes

Consultations

Department of Education Disability Action Plan
Child Poverty Strategy 2010
Fundraising news, Contact a Family text donations

Campaign news - Stop the DLA Takeaway update

Thank you again for your support of Contact a Family and the Children's Trust's campaign calling for the rules to be scrapped whereby Disability Living Allowance (DLA) is taken away from a child when they spend more than 84 days in hospital.

We are writing to update you on the campaign activities.

Unfortunately we have had a disappointing response from the Department of Work and Pensions. The department seems unwilling to act on our recommendations at this stage.

However due to your overwhelming support and the feedback we continue to receive from families, we have resolved to press on with the campaign.

In their letter to us the DWP argues that DLA payments are suspended because in a hospital "a patient's needs (are) fully met free of charge". We know that this is most definitely not the case as parents continue to provide high levels of care and their expenses increase.

The next steps for the campaign:

- We are writing back to the Department of Work and Pensions to rebut their arguments and tell them that we are continuing to call for these changes
- We are hoping to set up a meeting with a relevant Minister and a family who has been affected by these issues.
- We are gathering support from MPs. One MP has agreed to ask a Parliamentary Question about the campaign to increase awareness of it with politicians. We will of course let you know when this will take place and the response we get.
- Supporters are continuing to write to their MP to raise awareness of the campaign. We've had one family confirm that she has been asked to meet with her MP on the subject, which is great news.
- We have written to professional bodies, including the Royal College of Paediatrics and Child Health (RCPCH) and the Royal College of Nursing (RCN) to ask them to support our campaign.

Thanks again for your support and we will keep you updated.

Campaign news - Fuel poverty's icy grip tightens on our disabled kids

Belfast Telegraph by Lisa Smyth, in *Saturday, 6 November 2010*

Disabled children in Northern Ireland are more likely to be living in fuel poverty than any other part of the UK, new research has revealed.

A leading UK charity has said that the number of households with a sick or disabled child living without heating is 10% higher here than any other part of the UK.

Contact a Family is a member of the Northern Ireland Fuel Poverty Coalition which is calling on the Executive to eradicate fuel poverty.

Northern Ireland has the highest level of fuel poverty in western Europe and, as a result, some of the most vulnerable in our society are being put at even greater risk.

A report by the charity, Counting the Costs 2010, found that 34% of families in Northern Ireland with a disabled or sick child are going without heating – over 10% more than in the rest of the UK.

Frances Murphy, manager of Contact a Family in Northern Ireland, said the statistics highlight the need for Government action to eradicate the problem.

“Families of disabled children are particularly vulnerable to fuel poverty,” she explained.

“They often live on below average incomes and are more likely to be stuck indoors. Many conditions worsen in the cold weather, so parents are forced to have the heating on constantly.”

Ms Murphy called on Northern Ireland politicians to work together to implement a range of measures she believes will help to resolve the problem.

“Contact a Family calls on the Government to pilot the extension of a Winter Fuel Allowance of £200 to families with disabled children under five who are in receipt of DLA at the middle to higher rate of the care component and/or the higher rate mobility component.

“We also call on Northern Ireland Electricity and Airtricity to offer social tariffs and promote the use of the priority register to families with disabled children.”

A spokeswoman from the Northern Ireland Fuel Poverty Coalition said: “With over 10% of Northern Ireland’s population in receipt of Disability Living Allowance, there is a clear danger for those vulnerable households.

“Unlike those aged over 60 there is currently no support offered for individuals who are permanently sick or disabled.

“They must rely on their benefit entitlement to pay for high energy bills.”

Christmas carol downloads

Do you want to know the signs for Christmas songs? This year The Makaton Charity have added a further four carols to their range of downloadable carols: Away in a Manger, Silent Night, While Shepherds Watched, and I'm Dreaming of a White Christmas. Each song contains both the words and line drawings of signs. They are an ideal resource to use with friends and family or as part of a group activity.

<http://www.makaton.org/khxc/gbu0-catshow/christmas-carols.html>

£3.50 per song

New Service For Congenital Heart Disease Launched

A Nurse-led Congenital Heart Disease Transition Clinic for 14-16 year olds called rheartz was launched on the 10th December, by Health Minister Michael McGimpsey.

About one percent of babies are born with congenital heart abnormalities, ranging in severity from the most simple to the more complex. Often these babies undergo major life saving cardiac surgery during their infancy and again during their childhood years, and thanks to the advances in

medical treatments and surgical techniques, the majority of them now survive into their adult years.

As patients approach adulthood, their care will move from paediatric services to adult services, and many children and their parent can find this transition period difficult.

In response to this need, rheartz (pronounced 'Our Hearts') was developed as a Nurse-led Congenital Heart Disease Transition Clinic for 14-16 year olds.

The clinic is held in Bradbury Health and Wellbeing Centre twice a month, and aims to provide a smooth transition for patients from the paediatric to adult services for around 100 – 150 teenagers per year.

'Jan Gordon, Adult Congenital Heart Disease Nurse Specialist added, 'This is a nurse led service which concentrates on education, health promotion, empowerment and peer support. We hope to empower our patients to become experts within their own health'.

Special educational needs - A Guide for Parents

Just a reminder of the following information in regard to special educational needs.

The law dealing with Special Education in Northern Ireland is contained in the *The Education (Northern Ireland) Order 1996* as amended by *The Special Educational Needs and Disability (Northern Ireland) Order 2005 (SENDO)*.

The Department of Education has provided guidance for Boards and schools in the form of a Code of Practice on the Identification and Assessment of Special Educational Needs and also a Supplement to the Code of Practice, effective from 1st September 2005, which was produced as result of SENDO.

Schools, Boards and health and social services authorities must consider the advice given in the Code of Practice when deciding what they should do for children with special educational needs.

This booklet is to help you to understand:

- What special educational needs are.
- What schools, boards and others can do to help.
- What your rights are.
- How you can play a full part in your child's education.

An electronic version of the booklet is available for viewing by following this link to http://www.deni.gov.uk/index/7-special_educational_needs_pg/7-special_needs-a_guide_for_parents_pg/7-special_educational_needs_-_a_guide_for_parents-contents_pg.htm

Sorry for the very long address!

A copy of this booklet is also available by writing to:

*Special Education Branch
Department of Education
Rathgael house
43 Balloo Road
Bangor*

or by telephoning : 028 9127 9939

Lone parents on mid and high rate DLA exempt from changes to Income Support

Under a new scheme announced at the end of October lone parents with children aged seven and over will be required to claim Jobseeker's Allowance rather than Income Support if they are able to work – three years earlier than they do now.

However, following lobbying by EDCM and the disabled children's sector, the Department of Work and Pensions (DWP) has confirmed that lone parents will not lose their Income Support if their child receives the middle or high rate care component of the Disability Living Allowance.

In recognition of the extensive caring responsibilities of many lone parents of disabled children, and the impact that these caring responsibility have on their ability to search for employment, the DWP has announced that:

'Some lone parents will continue to receive Income Support if:

- They have a child in receipt of the middle or highest rate care component of Disability Living Allowance;
- Receive Carer's Allowance, or;
- Are Fostering'

They also announced a range of additional safeguards that underpin the scheme as follows:

- 'Lone parents with children of 12 or under will be able to specify school-hours only jobs without it affecting their benefits.
- A lone parent's availability for work must take into account their childcare responsibilities.
- A lone parent on JSA will not be expected to take up a job if appropriate childcare is not available.
- Work Clubs provide unemployed people with a place to meet and exchange skills, find opportunities, make contacts, share experiences and receive support to help them in their return to work.
- Jobcentre Plus staff will ensure that every lone parent is contacted before the changes affect them to give them enough time to claim another benefit or find paid work.'

Lady Allen of Hurtwood Trust - Travel Awards

Applications are now invited for the 2011 Lady Allen of Hurtwood Travel Awards.

Lady Allen was a pioneer in the field of children's rights and adventure play for disabled children. Grants are awarded to candidates working with children with a particular emphasis on those who work with disabled children and/or children from disadvantaged backgrounds.

The aim of the award is to offer candidates the opportunity to travel and broaden their professional experience which they can then apply to their work with children.

Application forms and guidelines (as well as further information about previous grants awarded and the life of Lady Allen) can be found by visiting the Lady Allen Memorial Trust website at:

www.ladyallentrust.org or by emailing Caroline Richards: LAMT@hotmail.co.uk

Please note that ALL applications must be posted (NOT SENT BY EMAIL) to: Caroline Richards, 89 Thurleigh Road, London SW12 8TY.

The closing date for completed applications is: **31st January 2011**.

Training - 'Made of Money', a 2 day 'train-the-trainer' course

This will enable you to deliver a 7 week course for families on low income around money is being offered in **Belfast on Wed 12th-Thurs 13th Jan 2011**.

'Made of Money' is an **innovative, creative and award winning family learning course** about money.

- It aims to help look at the emotion, values and attitudes around money as a whole family unit.
- It encourages **parents to help their children learn about money and consumerism**- covering topics such as 'why we buy things for our children', 'advertising and branding' and 'needs vs wants' as well as basics such as credit, debt and budgeting.
- It is all delivered in a very informal way, with cards, games, exercises, **plenty of chat and cups of tea!**
- We have found that it's a **great 'way in'** to help those families who would not necessarily take up money advice otherwise.

- You **don't need to have any background in financial advice** to deliver the course, as it's about facilitating discussion rather than offering advice. Families are then referred on for more specialised help.
- Training includes a **full ready-to-use set of reusable resources** to run the course over and over again. This includes all session plans, exercises, handouts, and 'cheat sheets' for facilitators.

Training is charged on a sliding scale based on ability to pay- plus a charge for resources purely at cost of materials.

For more information, or a booking form, please contact: madeofmoney@qsa.org.uk, 020 8983 5047 or check out our website:

<http://www.quakersocialaction.com/madeofmoney/Made-of-Money-partnership-work>

Alison Tsang
Partnership Worker
Made of Money & Moneytalk Islington

Quaker Social Action
working for a just world where people put people first

17, Old Ford Road, Bethnal Green, London E2 9PJ
Tel: 020 8983 5047
Fax: 020 8983 5069

Web: www.quakersocialaction.com

Grandparents matter? Invitation to attend a seminar.

Supporting and valuing grandparents in a society, whose family structures are increasingly diverse, is important. Professor Judith Dunn (MRC Research Professor at the Institute of Psychiatry in London) will share her extensive knowledge and expertise about grandparents, their role and their impact on children, which will inform service providers.

This event will be of particular interest to those who work with families in the statutory, voluntary and community sectors and wish to extend their knowledge about the role of grandparents in the family.

Locations and Dates: Tara Centre, Omagh. Monday 7th February 2011 or Belfast. Tuesday 8th February 2011 (exact venue TBC)

Cost: £15 per ticket. Admission by ticket only.

For further information please contact Sheila on tel 028 9031 0891 or email: sheila@pachelp.org

NAS - family support programmes

The following parent seminars/ help! and help! 2 programmes are provided free of charge to parents and to make a booking phone 028 9068 7066.

Title: Siblings

Venue: The Sandel Centre, Knocklyn Road, Coleraine, BT52 1WT

Date and time: 1st February 2011, 10.30am- 2.30pm.

This seminar is for parents /carers who have a child with autism who has siblings younger than 18. It focuses on the needs of the siblings and provides strategies for teaching them about their brother/sister and autism

Title: Managing Anger

Venue: The Sandel Centre, Knocklyn Road, Coleraine, BT52 1WT

Date and time: 2nd February 2011, 10.30am- 2.30pm.

this is a practical seminar for parents/carers that focuses on the communication strategies and dealing with difficult behaviour and anger, providing tips and coping strategies.

Title: Transitions: helping your child to move through the different stages of school

Venue: NAS, 59 Malone Road, Belfast, BT9 6SA.

Date and time: 16th February 2011, 10am-12pm

Practical tips to help with your child's transitions through school.

Title: Good home-school relations

Venue: NAS, 59 Malone Road, Belfast, BT9 6SA.

Date and Time: 16th March 2011, 10am-12pm

Includes advice on how to resolve problems and disputes.

Title: Siblings

Venue: to be confirmed

Date and Time: 23rd March 2011, 10.30am- 2.30pm

This seminar is for parents /carers who have a child with autism who has siblings younger than 18. It focuses on the needs of the siblings and provides strategies for teaching them about their brother/sister and autism

Title: help! Programme Lisburn Cost Free

Event Date

22nd March 2011, 23rd March 2011, 29th March 2011

Venue

Trinity Methodist Church, Knockmore Road, Lisburn, Northern Ireland BT28 2EA

Details

The help! family support programme provides information, support and advice for parents/carers, family members and people with an autism spectrum disorder (ASD). This particular three-day programme, starting on the 22nd March 2011, is for parents/carers of children aged between 5 and 11 years with a diagnosis of autism spectrum disorder (ASD). The programme provides basic information on the following: an overview of ASD's; tips for communication; practical strategies for education and educational rights/law; managing behavioural difficulties; and accessing support services and benefits. There is no cost to parents - refreshments are provided but please bring your own lunch. Up to 10 families, two places per family may attend (or one family member and a friend). Places will be allocated on a first come, first served basis.

Contact Address

Family Support Worker Administrator, Janine Vaughan, 59, Malone Road, Belfast BT9 6SA, tel: 028 9068 7066

Duration

3 days 9.30am to 2.30pm

Target Audience

Parents/carers

Department of Education Disability Action Plan - consultation

Under Section 49B of the Disability Discrimination Act 1995 the Department of Education is required to submit a Disability Action Plan to the Equality Commission showing how it proposes to fulfil its statutory Duties to:

- Promote Positive Attitudes towards people with disabilities; and
- Encourage participation by people with disabilities in public life (the disability duties)

The Department is consulting on its revised Disability Action Plan 2010-2013 until the 31st January 2011. If you have any comments, go to view the downloadable documents

<http://www.deni.gov.uk/index/85-about-the-dept/85-about-the-department-equality-pg/deprtment-of-education-disability-action-plan.htm>

or follow the links at <http://www.deni.gov.uk>

Child Poverty Strategy 2010 - consultation

The Child Poverty Act 2010 became law on 25 March - it requires the Executive to produce a Child Poverty Strategy. A draft strategy for consultation has been launched, which sets out the key areas that we believe are crucial in addressing the causes and consequences of child poverty and in meeting our obligations as detailed in the act. More importantly, it sets the strategic direction for the eradication of child poverty here and is intended to bring focus to the issue and promote a common aim cross government.

OFMDFM welcomes your views to help them finalise the strategy

Go to <http://www.ofmdfmi.gov.uk/index/improving-public-services/ofmdfm-consultations/ofmdfm-consultations-current-forthcoming.htm> for the following documents

* Child Poverty Strategy 2010

- * Questionnaire - Child Poverty Strategy
- * Child Poverty Strategy - children's version

OFMDFM will be holding a number of consultation events to discuss the draft strategy and to provide further opportunities for you to feed in your views. Full details of the dates, times and venues will be placed on their website shortly. **The consultation closes on 6 February 2011** so please tell them what you think before then.

NEW- Contact a Family, Text Donation Service!

Just a quick note to highlight that we now have a **Text Donation Service** as another alternative for supporters to donate to Contact a Family.

It's a really easy way for people to donate, and would be great if we are able to promote the number whenever you can!

We'll be using the text number at fundraising events, on our literature and it will be up on the website and social media sites. If you have a way to promote the number as well that would be grand to encourage as many text donations as possible over the coming year.

Why not start off by sending it to friends and family?

If you like, you can put the following statement on newsletters or any other relevant materials. It is valid until October 2011 so use freely until then

Text Family to 70007 and donate £3 to Contact a Family. You will be charged £3 plus one message at your standard network rate. Contact a Family will receive a minimum of £2.40 from each message sent.

Thanks

'In Touch' is issued every two months (end of August, October, December, February, April & June) and aims to bring you up to date news, details of training courses, group information and new resources available from within Contact a Family and from other organisations. We hope the information is useful and helps you and your family.

WE REALLY NEED YOUR FEEDBACK! about 'In Touch' and all our services and publications. Please take a few minutes to forward you comments to the e mail address below. Without feedback our funders don't see the value of various pieces of work we do!

Thank you to all those who did send us feedback it is very much appreciated

For right up to date information on events, consultations, local groups our most recent Newsletter and more see our webpage at www.cafamily.org.uk/inyourarea/nireland.html bookmark this page and then you can access it quickly!

We are available to help with any issues that affect the disabled child or young person, parents, families and professionals.

Contact us at 028 92627552 or e mail nireland.office@cafamily.org.uk



Please note that the Contact a Family office will be closed from:

5pm on Wednesday 23rd December

New year opening:

The office will open again on Tuesday 4th January 2011