



**30 years of
strengthening
families with
disabled children**

In Touch

Contact a Family - Northern Ireland Bi Monthly newsletter February 2010

In Touch is issued every two months 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.

For right up to date information on events, consultations, local groups our recent Winter 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

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1. NICCY- Work together to 'Make It Right'

In the run-up to the 21st anniversary of the signing of the United Nation Convention on the Rights of the Child (UNCRC) NICCY will be highlighting key areas of work that children, young people, parents, teachers and carers can get involved in.

Northern Ireland Commissioner for Children and Young People (NICCY), Patricia Lewsley, has launched a campaign to encourage children, young people, their parents, carers and teachers to 'Make It Right'. Twenty years ago the UK Government signed the United Nations Convention on the Rights of the Child (UNCRC) - a list of 42 promises the government has made to children and young people - but it has not yet become UK law.

Through the 'Make it Right' campaign children and young people are encouraged to write to government, develop their own campaigns and help make sure that the issues that affect children day-to-day are brought to the attention of decision makers and to make sure that the promises of the UNCRC are delivered.

This month the campaign is highlighting child poverty, which affects more than one in four children in Northern Ireland.

Find out more at www.communityni.org/news/work-together-make-it-right.

2. Unique Information Guides

In 2009 staff have produced 13 brand new information guides to specific rare chromosome disorders along with 8 full revisions to existing guides. There are now well over 100 guides, covering a variety of topics relating to specific chromosome disorders, including medical and behavioural issues. These are not available anywhere else

All Unique's information guides are available free of charge to download from our website at www.rarechromo.org

The most recent guides published cover Xq28 duplications, 12q deletions, 15q13.3 microdeletion syndrome and Emanuel syndrome. We have also published a guide to duplications of 7q in Spanish and deletions of 1p36 in French.

If you or someone you know needs help or information you can contact Unique by email at info@rarechromo.org at any time or by calling +44 (0)1883-330766.

3. Half Fare SmartPass - Disability Living Allowance

Eligibility

To be eligible to apply for this half fare concessionary travel pass you must be in receipt of either the higher or lower rate mobility component of Disability Living Allowance. The award of this benefit must also have been provided for at least 12 months, you must be aged between 16 and 59, and have been resident in Northern Ireland for a minimum of three months.

How to apply

Application forms can be obtained by telephone on 0845 600 0049 or by emailing your request to transport.policy@drdni.gov.uk

Terms and conditions of use

- Half Fare SmartPasses are issued for the sole purpose of providing eligibility for concessionary travel on scheduled services provided by Translink and other operators. A valid working SmartPass must be presented on every journey in order for free travel to be obtained otherwise the full adult fare will be charged for the journey
- Half Fare SmartPasses are valid only on scheduled bus and rail journeys made in Northern Ireland. They are NOT valid on cross-border journeys, or on journeys within the Republic of Ireland
- Half Fare SmartPasses are NOT TRANSFERABLE, nor are any tickets issued in conjunction with them
- Use of the Half Fare SmartPass is subject to the full conditions of carriage of the transport operator
- The SmartPass remains the property of the Department for Regional Development and may be withdrawn at any time
- After you have boarded the vehicle and requested your ticket, you should check the ticket to ensure that the details of your journey are correct. If the details are not correct, you should inform the driver/ conductor immediately
- The personal information which you provide on this form will be processed and held by Translink for the purposes of managing and operating the Concessionary Fares Scheme. The Department for Regional Development sponsors this scheme and may use non-personal statistical data collected and provided by Translink to analyse current and plan for future uses of the scheme. The Department may also use personal data provided by Translink to investigate cases of alleged fraud
- It is the responsibility of Half Fare SmartPass holders to keep their SmartPass in good working condition. If a SmartPass is lost or damaged the SmartPass holder will have to pay for a replacement and will not be refunded for any fares paid in the interim

4. React's Holiday Homes

Families can apply for a week's holiday at one of the mobile homes around the UK:

React's Holiday Homes

****NEW** Sandilands - Kilkeel, N Ireland**

The Mourne Mountains and the sandhills of Cranfield form a backdrop to this low density park with its own private sandy beach. It is quiet and peaceful, offers excellent facilities, yet is central for all the local attractions.

For further information please call **028 41763 634**.

Cala Gran - Blackpool

This lively, family resort is located near the bright lights of Blackpool, with its famous pleasure beach and theme parks. Just two miles from the seaside, the site itself has plenty of indoor and outdoor activities, including the children's Splashzone, Soft Play Area, Farm and a wide range of shops bars & restaurants.

For further information please call **01253 872555**.

Trecco Bay - South Wales

Located on the beautiful sandy beach at Porthcawl, this popular resort offers a fantastic selection of activities for children, including a water park, go-karting, bowling, outdoor and indoor play areas, adventure golf, Kids' clubs and much more. Families can choose from a range of on-site bars and restaurants or choose to explore Glamorgan's dramatic coastline with its castles and wildlife. Full details of Trecco Bay Holiday Park may be obtained from the site.

For further information please call **01656 782103**.

Wemyss Bay - Renfrewshire

The truly beautiful location on a wooded slope overlooking the Clyde, Wemyss Bay, is perfect for enjoying the scenic beauty of the West Coast of Scotland. Run by British Holiday, this small friendly park has a welcoming atmosphere with a great range of activities for all the family, especially in the evening when the family clubroom really comes alive.

For further information please call **01475 520812**.

Coastfield - Skegness

Close to the famous resort of Skegness, with its funfairs, long sandy beaches and donkey rides. Coastfield is the ideal way to enjoy a traditional family holiday. This site has an outdoor heated pool and sun terrace and is a few minutes walk from the sea. It offers a wide range of activities and entertainment and is within easy reach of shops, pubs and restaurants.

For information please call **01754 872592**.

Thorness Bay - Isle of Wight

Travel across the water to visit the scenic Isle of Wight. The React mobile home is situated on the very popular and friendly camp site. Guests can enjoy all the facilities this has to offer. A full entertainment programme catering for young and old alike can be enjoyed all day and every evening. (Please note there are no bus services from the Port to Thorness Bay, which is not easily accessible without a car). Full details of Thorness Bay Holiday Park may be obtained from the site.

For further information please call **01983 523109**.

The three-bedroom holiday homes are located in family-friendly parks and can accommodate six people in comfort. The homes are self-catering and site-fees are included.

Please note that unfortunately **mobile homes are not wheelchair adapted**. However if the holidays are unsuitable for your child React may be able to contribute towards an equivalent holiday if you send them the relevant information and prices.

Applying is exactly the same process as for other awards; just write *React Holiday* under 'Purpose of Application'. The form needs to be endorsed by a social worker, doctor or other health professional. The season runs from March/April to the end of October. You can call React to check availability or reserve a particular week until your application is processed at 02089402575 or e mail at react@reactcharity.org

For more details go to www.reactcharity.org/holidays.php

5. Training and Events

- **Peat Autism training for 2010**

Introduction

PEAT will deliver a series of Autism training through one day workshops . These workshops are targeted at parents, tutors and professionals working with children with autism. All PEAT training uses the principles of Applied Behaviour Analysis (ABA)

Cost for all the workshops is as follows; PEAT Parent £15, Parent £25, Student £20, Professional £60

Booking; To register your interest and/or secure a place for any of the sessions contact the PEAT office on 028 9032 4882 or e mail info@peatni.org as soon as possible

Workshop Title- Structured Teaching Methods

February 2010

Date Monday 15th February

Location and time L/Derry – 10am -3pm

Venue Ramada Davincis Hotel

Date Tuesday 16th February

Location and Time – Coleraine 10am – 3pm

Venue The Lodge Hotel

Wednesday 17th February

Location and Time – Enniskillen 10 am – 3 pm

Venue Killyhevin Hotel

Thursday 18th February

Location and time - Ballymena 10am -3 pm

Venue Leighinmohr House Hotel

Friday 19th February

Location and time Lisburn 10am -3pm

Venue Lagan Valley Island Centre

Monday 22nd February

Location and time Omagh 10am -3pm

Venue Silverbirch Hotel

Thursday 25th February
Location and time Armagh 10am-3pm
Venue Armagh City Hotel

There are workshops scheduled in the same locations **June 2010 - on toileting, sleeping and eating** and in **September 2010 - on Autism effective intervention** which will be advertised nearer the time.

- **Care for the Family in NI** are running 3 events entitled ***Teenagers! What every parent HAS to know***

The aim to help parents feel more confident about dealing with their teenagers and find out what is really going on in the teenage brain.

Out of a survey of 6, 577 parents 90% stated they felt more confident about parenting teenagers.

Cost - £6.00 each or if 4 or more booking together £5 each

Booking - By visiting www.careforthe family.org.uk/teenagers

Or call 028 92628050 and quote brochure

Time - events run from 7.30pm – 10pm doors open at 7pm

Monday 22nd February

Venue White Horse Hotel, 68 Clooney Road, L'derry BT47 3PA

Tuesday 23rd February

Spires Conference Centre, Church House, Wellington Street, Belfast BT1 6DW

6. *NEW!* Access for all- it's the Law!

As of the 25th January disabled people have new rights when accessing transport services in Northern Ireland. The Equality Commission have published guidance documents on the new rights which disabled people will have under the Disability Discrimination (Transport Vehicles) Regulations (NI) 2009.

The Disability Transport Regulations came into force on 25 January 2010 and cover trains, buses and coaches, taxis, vehicle rental and breakdown services. They make it unlawful to treat a disabled person less favourably than someone without a disability, for example by offering them a lower standard of service.

The Equality Commission has produced six leaflets covering the different transport groups for service users and transport operators. It is also producing a Code of Practice for transport operators which is currently with OFMDFM for approval. Commission staff has completed training sessions for transport providers during January and are happy to offer additional training on request, subject to numbers and feasibility.

One of the Commission's duties is to promote equal opportunities for disabled people. They believe the Disability Transport Regulations will make a positive and practical contribution to enabling disabled people to realise new opportunities for work and leisure that may not have been open to them before.

For a copy of this document contact the Equality Projects Administration team at equalityprojectsadmin@equalityni.org or go to www.equalityni.org and follow the links under publications. Here it is available in word and PDF formats as well as audio and video clip with BSL.

7. *NEW!* Lisburn City Council - Volunteering awards

Volunteering continues to be a vital element within the community and voluntary sector. The Mayor's Awards for volunteering 2010 aims to recognise and promote the important role that volunteering play in building and improving our society and environment. The Mayor's awards for volunteering is inviting nominations under four separate categories

Young Volunteer of the year,

Adult Volunteer of the year,

Supporting Volunteering of the Year Award (Large Group) and

Supporting Volunteering of the Year Award (Small Group)

A gala evening in June 2010 will showcase the rewards and work of volunteers within the Lisburn City Council Area.

Get your nomination pack from Rhonda Frew, Community Development Officer, Bridge Community Centre. 50 Railway Street. Lisburn BT28 1XP, tel 02892662496 or e mail Rhonda at rhonda.frew@lisburn.gov.uk the packs can also be downloaded at www.lisburncity.gov.uk

All nominations must be received by 4pm on Friday 19th March 2010

8. The Knights hat trick!

Junior wheelchair basketball champs come home victorious after a gruelling 3 matches in one day, but the tired bunch of kids kept smiling after putting in a great team performance. You can read more about the matches and get more information about the Knights at www.niknightswbc.btik.com

9. *NEW!* Developing a Disability Strategy for NI - improving outcomes and support for those with a physical disability, communication and/or sensory impairment.

A broad ranging group of service providers and people with disabilities and their families came to contribute their thoughts and experiences to this Strategy on Thursday 28th January in the Lagan Valley Island, Lisburn. A similar group also met in Omagh on the Monday. The workshops were co coordinated by the Mental Health and Disability Directorate of the Department of Health, Social Services and Public Safety. Aply facilitated by Richard Dixon, Patient and Client Council Director, the viewpoints and thoughts of the groups were gathered and will be incorporated into the Strategy. If you want to contribute your thoughts to this process e mail

bernie.redmond@dhsspsni.gov.uk or tel 028 90522543, and share your experiences of accessing services, what you cannot access, what key outcomes you would like to see from this Strategy and any suggestions you have to offer to make this work valuable and beneficial to you as a parent and for your disabled child or young person.

10. *NEW!* Family Support in the Southern Trust- can you access services, is the information available to you?

These were the questions put to a group of Service providers from the voluntary and community sector. Children's Services Planning in the Southern Trust area are concerned with the development of a process to ensure earlier access to Family Support services for children and young people in the area. Their ethos is 'supporting families is everybody's business' They are interested in finding out;

how easy or hard it is to access information about family support in the area,

are there any examples of good practice that could be shared?

what do you think needs to be done to access family Support better and

any other comments you may have on this subject.

If you have any thoughts on the subject put your thoughts to Paul Morgan , Assistant Director of Family Support and Safeguarding at paul.morgan@southerntrust.hscni.net or Ann Godfrey , Children's Services Planner, Southern Area C&YP Committee at ann.godfrey@hscni.net or tel 028 3741004110

11. *NEW!* Debt service for N Ireland – a free confidential and impartial local Money Advice service for all the community

A new face-to-face debt advice service is aimed at extending the facilities available to those in need across Northern Ireland.

Announcing an £825,000 contract from her department to fund Debt Action NI, Arlene Foster said the new service would compliment existing debt advice services, reaching into areas and sectors of society where they had not previously been available.

The free service will now extend to Armagh, Ballymena, Cookstown, Downpatrick, Limavady, Lisburn, Magherafelt, Moyle and Strabane.

"In these times of increased financial difficulty, my department wants to help those consumers in greatest need," said Mrs Foster.

"Advice will be available in neutral surroundings, on a wide range of issues including debt, benefits, housing, tax, employment and consumer issues."

"The 16 additional debt advisors will help to ensure assistance is available to those in financial difficulty at the earliest opportunity."

For details of how to contact your local advisor, telephone 02890645919 for information.

12. Disability Action – what products have made your life easier or are a waste of money!

Disability Action in conjunction with the NI Housing Executive are looking for people with a range of disabilities and carers from across NI to take part in a research study in early 2010. The research will give you the opportunity to recommend products that have made your life easier or to highlight difficulties you are having with particular products. The recommended products will be included on a list, some of which will be reviewed by a Products Working Group.

If you would like to take part in the research study you can submit your story or register your interest online at www.disabilityaction.org/housing or contact Laura Cleland at 02890297880 or e mail lauracleland@disabilityaction.org

13.**New!** Resources from Contact a Family

- ***Cash counts for families with disabled children hit by January blues***

Contact a Family has launched Cash Counts, a new online service dedicated to ensuring families with disabled children are getting every penny.

Cash Counts includes:

- An online benefits calculator, allowing families to work out how much they are entitled to
- A top tips guide on the benefits available to families with disabled children written by the Contact a Family helpline
- A frequently asked questions page to help families navigate the complex benefits system.

Srabani Sen, Contact a Family Chief Executive, said: “Cash Counts gives families with disabled children the latest financial advice and information specific to them and all in one place.

“It costs three times more to raise a child with a disability, so families with disabled children are more likely to be living in poverty and be reliant on benefits. In these tough economic times, finances are tight for all families, but for those with a disabled child things are even harder. They need a helping hand to navigate the complex benefits system.”

Families with disabled children face enormous financial challenges. They incur additional costs caring for their child – childcare, heating, transport, home adaptations and equipment. It can also be difficult for families to hold down a job due to the demands of caring. Despite this, many are not claiming the benefits they are entitled to.

Mum, Stephanie, said: “My husband recently stopped working because the strain of working and caring for Isaac was too much. It has meant we have had to tighten our purse strings. Isaac is doubly incontinent and this means clothes, bed linen and furniture need replacing far more frequently than is usual. And we have the washing machine on

at least twice a day often doing a boil wash. This is not something we can reduce, so we have to incur the extra costs.”

Srabani Sen added: “We would urge families with a disabled child to use Cash Counts or telephone the Contact a Family helpline to make sure they are getting every penny they are entitled to.”

Go to www.cafamily.org.uk/cashcounts

- ***New podcast on Spina Bifida and Hydrocephalus***

A mother discusses her experience of having one of her twins diagnosed with Spina Bifida and Hydrocephalus.

Go to www.cafamily.org.uk/news/podcasts.html

Your feedback on this e newsletter is valued. A few words or whatever you have time to put together would be greatly appreciated.

Please e mail your comments, suggestions or thoughts to.
catherine.flannigan@cafamily.org.uk

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