

in contact

The Contact a Family newsletter

Northern Ireland

“Our Family Our Future” report

local families join us at launch in Parliament Buildings

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nireland.office@cafamily.org.uk
www.cafamily.org.uk/nireland

The full report is available to download at:

<http://www.cafamily.org.uk/publications.html?scat=16>

or to order from the online shop.

As part of the 30th anniversary celebrations Contact a Family has compiled a report outlining the stories of 30 families from around the UK.

The four families from N Ireland, who contributed their stories, were given special recognition for their contribution to this report at its launch in the Long Gallery. Their photos, featured in the report, and on display with the other 26 families, took pride of place as the issues families face were highlighted with many local MLA’s, councillors, other voluntary organisations and community groups.

Patricia Lewsley, Children’s

Commissioner for N Ireland, congratulated the organisation on all its work and achievements over the past 30 years and particularly here in N Ireland over the past 10 years.

Trevor Lunn, MLA and Dominic Bradley MLA also voiced their support for the work of Contact a Family and how it has had a positive impact on the lives of families with disabled children across N Ireland.

Gemma Gurney, mum to Ellie , Hannah and Rebecca who has a rare chromosome disorder – deletion 6q13q14.2 , spoke about her experiences and the utter loneliness of having a child with such a rare disorder.

Families with disabled children celebrate family life despite facing bureaucracy and prejudice

Families with disabled children have the same hopes and dreams as other families, but are often prevented from achieving them by prejudice and lack of understanding.

That's the finding of a new Contact a Family report *Our family, our future* which features the stories of 30 UK families whose children are affected by a range of disabilities and rare conditions.

Paula McManus and Robert Keatings from Belfast, tell their story, featured in the report, and what life is like for them along with their daughter Rachel aged 3 and their son Gary, 5. This little boy who has Cerebral Palsy, is blind, can't talk or walk and he'll probably never be able to feed either.

"My husband and I are full time carers for our children. I would like to go back to work but it would be too much. Everything we do is to suit Gary's needs. If he doesn't

get the things he needs he'll just be miserable and then we'll be miserable, but it often feels like there's no one out there who will help you.

Gary also has seizures and he's totally dependent on others for his care. The family were told that Gary had Cerebral Palsy when he was born, but at that stage they didn't really know what it meant and it is only in the last couple of years that it has started to make any sense.

Gary's sister Rachel also has health problems; she was born with a massive hole in her heart. Despite having corrective surgery her mum still has to take extra care over dental care, infections and Rachel over exerting herself.

The main problem Gary has is getting a suitable wheelchair that he is comfortable in as he spends all his time in it. He struggles to get out of it.

It all takes far too long to get anything; an assessment took 6 months, then another 6 months to get the chair and by that time Gary had grown out of the wheelchair, so he was no better off.

"Sometimes all I do is sit and cry over his chair" Paula says

Our greatest achievement was getting Gary a bike. He went to America for treatment after 5 months of fundraising with our family. So now his daddy takes Gary out on his bike every day and Gary loves it. He gets to pedal and his hands are up, he's more relaxed... The difference is unbelievable. But the treatment Gary gets here in Belfast should be first class too. Sometimes it just feels as if people thinks he's disabled, so he doesn't matter.

Contact a Family would like to see families with disabled children given the same opportunities as others and is calling for:

- Government to invest in a campaign to raise awareness of the needs of families with disabled children.
- Stronger focus on disability awareness taught in early years and schools.
- People working in a public facing role to be given disability and equality training – so that they can recognise the unique talents that children bring – because of their disability.

How are your finances affected by the latest budget?

Changes in carer's benefits rules will help more families with disabled children claim

From 12th April 2010 Carer's Allowance, the only state benefit specifically aimed at carers, will be made available to a greater number of those who are working.

Carer's Allowance cannot be paid to a carer if they work and earn more than a set amount. The government has announced that this earnings limit will be raised from £95 to £100 after tax deductions - the first time it has been changed since 2007.

For working families caring for a disabled child, the Carer's Allowance rules allow certain childcare costs to be deducted from earnings, so some may qualify even though they are earning slightly more than £100 per week.

From April, Carer's Allowance will also rise from £53.10 per week to £53.90.

Srabani Sen, Chief Executive of Contact a Family: "It's good news for working families with disabled children who provide 35 hours a week of care but are just missing out on Carer's Allowance.

"Working families with disabled children are under enormous pressure juggling their employment and caring responsibilities. It is vital that they ensure they are getting all the financial support available to them."

Contact a Family's free Helpline can advise families with disabled children who want to know if the change in the rules will help them claim Carer's Allowance.

Call 0808 808 3555.

To help you ensure you are getting information to help you manage your money Contact a Family have up to date information in the following publications:

The updated version on Dealing with debt in N Ireland is now available to download from

<http://www.cafamily.org.uk/pdfs/debtNI.pdf>

To qualify for Carer's Allowance you must meet the following criteria:

1. Be aged at least 16 years old.
2. Provide at least 35 hours per week care to someone who gets either Disability Living Allowance at the middle or highest rate or Attendance Allowance.
3. Not be studying on a course involving 21 hours or more supervised study.
4. Meet certain residence and immigration conditions.
5. Have weekly earnings below the earnings limit.

Child Benefit...

There are two separate amounts currently paid for child benefit, with a higher amount for the eldest, or only, child.

The payment stands at £20 a week for the eldest child and £13.20 a week for each other child. These payments will go up to £20.30 and £13.40 respectively.

DLA...

Similarly the increase in benefits payments will only be marginal, with the highest rate of the care component of the disability allowance going up by 71p to £71.06.

Community Care Grants publication downloadable at
<http://www.cafamily.org.uk/pdfs/CommunityCareGrants.pdf>

Tax Credits for the self employed is downloadable at
<http://www.cafamily.org.uk/pdfs/TaxCreditsSelfemployed.pdf>

If you cannot access a computer or printer they can be requested through the office at 92627552 or by e mail at nireland.office@cafamily.org.uk

Loss of valuable Family Support Service

Contact a Family, N Ireland loses a very valuable service due to lack of funding. At the end of March 2010 the Family Support Service, Eastern Area, having provided vital support to families of children and young people with a wide range of disabilities ended.

Families who live in the Belfast, South Eastern and Southern Trust areas are devastated and outraged at the loss of this "lifeline", and their very valued Family Support Officer, Karen Patterson who has worked tirelessly with local families for 3 ½ yrs.

This post was funded initially for 3 years by the Big Lottery and the

Health Board for a one off 3 month period. Despite very determined efforts to secure ongoing funding from statutory and other sources, no funding has been forthcoming.

All telephone enquiries can be directed to the Lisburn Office, tel 028 9262 7552 or by e mail on nireland.office@cafamily.org.uk and the Family Support Service for families living in the Northern Trust area remains operational.

The staff at the NI office hope that you will join with them in thanking Karen for all her committed work during the last 3 ½ years and wishing her all the best for the future.

Calling all parents and carers out there...

All we need is your email address

The bi monthly "In Touch" newsletter is full of useful dates for events, new legislation on disability and up to date information on happenings that affect you and your disabled child. It is local and full of useful resources and information that can help you. All we need is your e mail address and it will be there every two months on your computer keeping you informed. Please send your details today to nireland.office@cafamily.org.uk and under subject put E ZINE. Thank you!

Multi disciplinary approach to care Working together to support families...

When I had my son, who has Down Syndrome nearly 21 years ago, I had suggested that it would be very beneficial for parents with children with additional needs that a "Clinic" where all the professionals who dealt with our children would be present. This is now happening in several health care settings within the Northern Trust Area.

As the Family Support Officer for the Northern Trust Area one of the most important places I wanted to be able to work in partnership, when I came into the post, was the Multi Disciplinary Clinic (MDC) in the

Robinson Hospital, Ballymoney. I felt my input in addition to the other staff present would be important as well as impartial to parents and children attending. I am the only non Trust staff member in attendance.

Dr Deirdre Walsh is Consultant in charge of the MDC and it is a very relaxed, informative environment. Parents and carers are offered the chance to meet the various professionals who are involved with their children and young people. It runs most Tuesdays from 10.30am until 1pm.

At the "New Patient Clinic" each staff member is allocated 15mins –30mins to talk to parents and give



information about services, care, and what can be provided for their children. I usually arrange to do a

Family support services

follow up Home Visit with the family where I provide extra support. Although the clinic can be a long morning and a stressful time for parents I know they feel it is worthwhile, as they can hear how their child is progressing from all those involved in the care, under one roof, at one appointment. Parents are also encouraged by Dr Walsh to ask questions, and participate in decisions regarding their child's condition and treatment.

It has been good to have the opportunity to discuss parents' needs and worries with the other staff and hopefully raise awareness of the stressors of caring for a child with a disability. A few weeks ago after a discussion with the Senior Ed Psychologist as to why parents feel so stressed regarding the Educational Statementing Process, I have now been invited to the Team Meeting of the Educational Psychologists, to inform them how parents feel about this process and hopefully this will

have a positive outcome for parents. I have been made very welcome by Dr Walsh to the MDC and she involves me in discussions and will refer parents to the Family Support Service. It has taken some time for others to accept my presence there but as a team we are all there to support families together.

Virginia Maxwell

New! Lisburn CONKeRs... support group off to flying start...

Sarah Hillis, mum of Luke, Hope and Imogen has set up an informal group to offer support to local families of children with complex needs and severe disability. The group may be small with about 8 families at present but hopes to reach out to as many families in the area as possible, offering support, a place to share your experiences and be listened to by like minded people.

The group meets every 3rd Wednesday in the month over a coffee; to find out more and go along yourself. Contact Sarah on tel **077 3646 7588** or **028 9258 6180** alternatively email: keepsmling.sarah@googlemail.com

Hope's New Play area

Thanks to Make a Wish Hope has fun

Hope lights up a room with her smile and the mischievous twinkle in her eye as she looks around to see where she can play and what she can play with. She is just another inquisitive 3 year old, despite all her difficulties. Hope was born prematurely at 25 weeks and as a result of this has cerebral palsy, hydrocephalus, chiari malformation and bronchopulmonary dysplasia amongst some of her diagnosed conditions. She has had numerous hospital admissions and her complex health needs require round the clock care from her parents Sarah and Sam, who also have to care for Luke, 11 and Imogen 8 months who both have disabilities.

November 2009 saw the completion of a housing adaptation to the Hillis home which has provided a downstairs bedroom and shower room for Hope. However the lack of a safe and appropriate play area in the small garden meant Hope could only look out the windows most days and not actually get outside and

enjoy suitable outdoor play facilities.



Thanks to an application to Make a Wish Foundation completed by Karen Patterson, Family Support Officer for Contact a Family, the cost of a safe "soft play surface" was granted. Hope can now get outdoors and enjoy the same freedom of play with access to suitable toys and equipment that other 3 yr olds have. Her smile is even broader than before as she tries out new toys.

Family support services



Cerebra works to promote, protect and improve early neurological health and well being. It funds research; facilitates understanding and knowledge; supports parents and carers; and provides direct financial support to children with related conditions.

They have a freephone helpline **0800 32 81 159**.

It is open Monday to Friday 9.30am – 4.30pm and an answerphone at all times.

E mail info@cerebra.org.uk
www.cerebr.org.uk
Fax 01267 244201

Address: 2nd Floor Offices,
The Lyric Building, King Street,
Carmarthen SA31 1ZY

Freepost address: Parent Support,
Cerebra, FREPOST SWC3360,
Carmarthen SA31 1ZY

This organisation provides such a range of services to children and families of children with all types of neurological conditions including ADHD, autism and cerebral palsy. The following information gives you some idea of the work they do, go to the website at www.cerebra.org.uk to see more.

Speech and language voucher scheme ... for children aged 1 to 16 with a brain related or neurological condition, your child must have a stage 4 or 5 SEN statement. The young person must not have received direct or group speech therapy in the last 6 months. If you have received a voucher before, you cannot apply again. If successful, the voucher is worth up to £500 towards therapy. For more information and an application, contact Alex on 0800 328 1159 or e mail alex@cerebra.org.uk. The application form can also be downloaded from the Cerebra website.

Wills and Trusts Voucher Scheme ... is for children aged 16 or under with a neurological or brain related disorder and in receipt of the middle or high rate care component of DLA. The voucher is worth up to £350 towards the cost of a solicitor or professional Will service and discretionary trust to make provision for your child's future. The contact details are as above.

Innovation Centre... helps with sourcing equipment, design problems, developing prototypes from your inventive ideas and designs. The team of dedicated engineers and designers also review existing products and give you a good product guide on the value of that product. One product well under way to production is the epilepsy hat. Contact them for more information on this product or any queries or issues with equipment or products for your child or young person.

Postal lending library... Cerebra's Postal Lending Library is a free resource for parents and carers of brain injured children and others

involved in their care, such as teachers, social workers and medical professionals.

They hold books on a wide range of topics to do with neurological conditions and other related issues, such as education and welfare. They also have a library of sensory toys, designed to help development. You can borrow 2 books at a time for 28 days and 1 sensory item for 1 calendar month. There are no postage charges as you can use the freepost address to return books and all toy deliveries and collections are made by a courier, which Cerebra organise. All book reviews and suggestions for the library are most welcome. If you find a book particularly useful, please recommend it to them and they will look into obtaining it for the library. Alternately, you may wish to donate it for others to enjoy.

DLA guide... A step-by-step guide to help with claiming Disability Living Allowance (DLA) for children under 16 with brain related conditions. Cerebra have produced a 63 page, step-by-step guide to claiming DLA for children under 16 years of age who have a brain related condition. The guide takes readers through the claim pack, box-by-box, and contains lots of useful hints and tips on: preparing for a medical visit; obtaining supporting evidence; keeping a DLA diary and much more.

To download your copy go to http://www.cerebra.org.uk/parent_support/DLA_guide

Or e mail info@cerebra.org.uk or phone **0800 328 1159** to request a copy.

MakingContact.org... linking families through Contact a Family

"I searched for ages to find someone with the same condition as my son. When I found someone through MakingContact.org who knew what I was going through - I was so happy, I cried."

Mother, Northern Ireland

When you or your family is affected by disability or a medical condition, it can sometimes be an isolating experience. Often being able to contact someone who knows what you are going through can be the biggest help but how do you find those people?

Contact a Family has been putting families with disabled children in touch with each other for over 25 years. MakingContact.org complements our existing services and gives you the chance to safely and easily get in touch with others who are affected by the same or similar disabilities or medical conditions as you are.

With thousands of medical conditions and disabilities listed and thousands of people signed

up and looking for contact, this site could help you find the people you are looking for. Your child doesn't even have to have a diagnosis, just enter undiagnosed. It's safe and easy to use.

Finding people, posting your details and replying to others is free. There is a nominal annual charge if you want to initiate contact with others.

A full list of all conditions is available in either alphabetical or hierarchical forms. Note that there are over 2000 conditions and these lists may take a few seconds to display

You don't have to enter the full name of the condition, abbreviations, parts of the name & wildcards (*) are acceptable.

There is also a message board facility where there are boards covering Education, Behaviour, Working, Growing up and Transition, Consultations, questionnaires and events and Share your Day.

<http://www.makingcontact.org/>

Positive Futures... Children and Families Services

This is a NI based charity providing a range of services to children, young people and adults with a learning disability. Their Head office is at 2b Park Drive, Bangor BT20 4JZ. tel 028 9147 5720 or e mail info@positive-futures.net

They provide support services for families who have a child or young person with a learning disability. Families Services aim to support the whole family, by providing opportunities for children and young people with a learning disability to get involved in the community and the possibility for parents, brothers and sisters to enjoy fuller family and social lives.

These Families Services are available in Lisburn, Co. Antrim; Bangor, Co. Down; Lisnaskea, Co. Fermanagh; Ballymoney, Co. Antrim; Coleraine; Co. Londonderry.

Autism NI... Family Support Team

The Family support teams are based in the South Eastern Trust area and offer advice, support and information on resources for parents, carer's of children and young people with Autism and Asperger's syndrome. Referral to this service can be made via the diagnostic team in the SEHSCT after an initial diagnosis of ASD is made, alternatively a referral can be made directly to the free Helpline number at **0845 055 9010** which is open Monday, Wednesday and Friday 10 am – 1 pm and available to anyone in N Ireland who needs assistance.

Child friendly seizure diary...

The NCYPE have produced a fabulous diary to help children with epilepsy aged 5-10 to record their seizures in a fun way. This is a lovely book with fun pictures and cartoons and is available free of charge by calling 01342 832243 ext 296 or email <http://info@ncpye.org.uk>

Transition – find local N Ireland information around the issues of transition and transition plans at http://www.cafamily.org.uk/pdfs/transition_ni.pdf in a downloadable booklet.

SNIP downloads... free resources mostly for teachers but some may be useful to parents including a list of free to use software for home access to computers and an A-Z on SEN
Go to www.snip-newsletter.co.uk/downloads.php

TES Connect... hundreds of free teaching resources for children with special needs.
Go to <http://tinyurl.com/yjx2ybn> and www.teachingideas.co.uk

The Pops reading programme... designed for children who are struggling to read, reluctant readers, children with ASD and Downs syndrome or with speech and language difficulties. Free manual contains tips, whether or not you buy the books. Go to <http://www.popsresources.com/>

Rareshare... new international social hub for patients, families and health professionals affected by rare disorders. Go to www.rareshare.org/

Seamless socks... does your child have difficulty tolerating socks with seams that "feel weird" and get on their nerves. You might want to consider these soft tube socks that are truly seamless.
Go to <http://www.sensory-smart.co.uk> to see more.

Family Fund N Ireland... From the 1st April there are new application packs available with new criteria. New income limit raised to £27,000
For more information go to www.familyfund.org.uk, tel 0845 13045 42 or e mail info@familyfund.org.uk



Mailing list

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Please remove me
from your mailing list.

Please send my Newsletter Via Post or Email

Name

Organisation (if applicable)

Address

Postcode

Tel

Email

Please detach and return this form to:
Contact a Family N.I.

Bridge Community Centre, 50 Railway Street, Lisburn BT28 1XP

Tel: 028 9262 7552 E-mail: nireland.office@cafamily.org.uk

Web: www.cafamily.org.uk/nireland Freephone Helpline: 0808 808 3555

I am: a parent/carer
 a parents' group contact
 a professional

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