

in contact

The Contact a Family newsletter

Northern Ireland

Family Fun Day

Sunday filled with laughs!

"Great fun!"

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July 26th dawned cloudy and showery but that didn't dampen the fun and laughs our families had at Horizon House. Puppet shows, magic tricks and the Mad Scientist made this Family Fun Day, funded by Energy for Children and hosted at the NI Children's Hospice, a great success.

The event was attended by over 16 families and approximately 40 children from the Greater Belfast area. Feedback was very positive and everyone had only good things to say:

"Thank you, everything was much appreciated, great fun!"

"It has been a good day; all the children have really enjoyed it"



30 years of strengthening families with disabled children

Attitudes towards disability shocking say UK families with disabled children

What makes my family stronger report

Families with disabled children in the UK feel stigmatised and shut out from society, according to recent research published by Contact a Family.

Contact a Family surveyed 615 families with disabled children about their experiences of living in the UK, asking what makes you stronger practically, socially and emotionally.

What makes my family stronger found negative attitudes towards disability coupled with a lack of services are the main barriers preventing families with disabled children from leading ordinary lives. While some families show resilience, imagination and great strength attempting to overcome these barriers, there are some who cannot cope any longer and are at breaking point.

Key findings of the *What makes my family stronger* report are:

- Almost 70% of families with disabled children said that understanding and acceptance of disability from their community or society is poor or unsatisfactory.
- Over 60% of families said they don't feel listened to by professionals.

- Vital support services such as short breaks, a key worker and childcare are unavailable to almost half of families.
- Over 60% of families said they don't feel valued by society in their role as carers.
- Half of families with disabled children said the opportunity to enjoy play and leisure together is poor or unsatisfactory.

Srabani Sen, Chief Executive of Contact a Family, said: "It is shocking that in the UK today, attitudes towards disabled children, from professionals and members of the public, are among the barriers preventing families from leading ordinary lives. Families with disabled children have enough challenges to overcome to secure the support they need without also having to cope with prejudice and ignorance."

Contact a Family is calling for:

- The government to invest in a UK-wide campaign to raise awareness of the needs of families with disabled children.

- Everyone working in a public facing role in the UK to be given disability equality training.
- A stronger focus on disability awareness in schools.
- The government to commit to urgently reviewing carers' benefits and set a clear timetable for reform.

Contact a Family welcomes the government's recent investment in services for disabled children and their families, but there is still a long way to go before the right support is available to all who need them.

Srabani Sen added: "Families with disabled children want the same things as other families. They want to see their children reach their full potential, they want to be included and accepted by their community and they want to enjoy time together and have fun.

"For this to happen, professionals need to recognise each child's capabilities rather than seeing only disability. They must also recognise the value and expertise of parent carers. And every one of us needs to be more understanding and accepting of disability."

National minimum wage increase... from October 2009

From October 1st, the national minimum wage increased to £5.80 per hour, £4.83 for workers aged 18-21 and £3.57 to those aged under 18.

Calling families affected by suspension of benefits when disabled child hospitalised

Parents, this is your chance to contribute your viewpoint to this campaign.

Contact a Family is looking for families whose children have had their Disability Living Allowance (DLA) suspended after a stay in hospital. Families from Northern Ireland are asked to contact Elaine as she wants to get feedback from across the UK.

At present DLA regulations state that if a child under 16 is in hospital for more than 12 weeks their DLA payments are suspended. For young people aged 16 and over the payments are suspended after only four weeks.

This can impact on a parent's entitlement to continue getting Carer's Allowance.

Contact a Family thinks this is wrong and we are gathering evidence from families about the effect of this benefits rule, to highlight the issue and push for change.

Claire Pimm, Director of Policy and Communications, said: "Children who have long-term health needs are often in and out of hospital and this puts tremendous pressure on

their families. It is wrong that they are financially penalised at such a difficult time.

"If your child's DLA has been suspended after a stay in hospital please do get in touch. We would like to gather as much evidence as possible so that we can highlight this issue and encourage change in the regulations."

Telephone: Elaine Bennett on 020 7608 8741 or e-mail: elaine.bennett@cafamily.org.uk

Lone parents...

...changes in benefits

From 26th October 2009, lone parents with a youngest child aged 10 or over will no longer be entitled to income support solely on the grounds of being a lone parent. They will instead have to transfer to jobseeker's allowance. If you were entitled to IS as a lone parent immediately before 26/10/09 and youngest child was at least 9 but not yet 12 then you can continue to receive IS as a lone parent until:

- If your child's 11th birthday is before 1st Feb 2010, until the first work-focused interview you have after 31/1/09.

- If your child is 10 and turns 11 after 31/1/09, until his/her 11th birthday.
- If your child is 9 but turns 10 before 6/6/2010, until the first work-focused interview you have after 6/6/2010
- If your child is 9 but turns 10 after 6/6/2010, until their 10th birthday

Please note that special rules allow some full-time students whose youngest child is aged over 10 to continue receiving IS as a lone parent until their course finishes.

Calls to Gingerbread

...now free

Calls to the Gingerbread Single Parent Helpline from all landlines and all major mobile networks are free of charge, with the introduction of a new number:

0808 802 0925

Supporting families in the Northern Board

Virginia Maxwell, Family Support Officer in the Northern Trust Area, reports.

Since joining the NI Team in February 2009 I have been out and about raising awareness of the service with a wide range of statutory, voluntary and community groups and very quickly received referrals for families with disabled children in need of support and help. There is a great need out there and I am delighted to be part of this vital service and able to offer help to families.

My background includes having trained as a nurse some years back and several years experience as a Volunteer Rep for Contact a Family. I was always impressed by the ethos of the organisation and how they supported families and their children. Not only that, but the wealth of good literature produced for parents and carers, and the links with other families in similar positions.

I guess my greatest experience comes from being a parent of two children, one of whom has Down Syndrome. I remember only too well how the information and publications we were given by Contact a Family really helped and informed us as a family.

The Northern Health Board area is quite a size to cover, especially as I only work 17.5 hours a week, but I do hope to be able to give support and information to as many families and professionals as possible.

My details are at the end of this article, please contact me if you feel I can be of any help to you – whether you are a family with a disabled child or a professional working with children who are disabled aged from birth to 19.

Virginia Maxwell
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Deborah and Jack with Virginia Maxwell, Family Support Officer

Ballymena Parents Group relax and share stories over a cup of coffee on October 20th at Monkey Business

Linda and Esther share tips



Anna and her daughter Ruby have fun

News from the Eastern area Family Support Service – funding

Many of you will be aware that we were very concerned for this service that covers the Belfast, South Eastern and Southern Trust areas. It was under severe threat of closure and due to cease at the end of September due to lack of funding.

We are delighted at this time to tell you that we have secured one-off, non-recurrent funding for 3 months, commencing 1st October 2009, from the Regional Health and Social Care Board. This has come as a great relief to the organisation here in Northern Ireland and to our very dedicated and hard working Family Support Officer, Karen Patterson, whose post it secures, for now. It also gives us a breathing space to renew our determined efforts to secure longer term and recurrent funding for this vital work. A BIG "Thank you!" to all of you who wrote letters of support and lobbied our Health Minister and your local MLA's on our behalf. It paid off! Also, many thanks for your generous donations which will go directly to supporting this post. Please continue to lobby for this vital work. With your voice being heard, the Health Trusts and Board will understand the great need for the Contact a Family Support Service that is provided to your family and families just like you.

What does this vital support mean to families?

A mum's story...

My name is Gemma, and my daughter Rebecca has a rare chromosome disorder – deletion 6q13q14.2. Rebecca was diagnosed with this disorder when she was 1 year and 6 months old. As the Genetic Consultant did not have any specific information on this disorder, she referred me to Unique and Contact a Family. We left the hospital not knowing what the future held for Rebecca and our family. Her condition is so rare there is no specific support group for it and, as we later found out, Rebecca is the only child in the whole of the UK with this particular chromosome deletion.

After a few days of letting the news sink in we lifted the phone in despair to Contact a Family. I was greeted by a friendly voice and immediately reassured by Frances that they could help and was referred to their Family Support Service. Karen Patterson came to visit us in our home.

Contact a Family has thrown our family a lifeline and without this invaluable service we would be isolated and totally on our own. Karen has provided me as a parent with endless vital information and leaflets on services and special equipment. She helped us to get funding for a special 'weighted blanket' to help calm Rebecca and give her a feeling of security. She has taken time to help me complete DLA forms, which are so complicated I couldn't have done it on my own.



Gemma with her 3 daughters – Ellie, Rebecca and Hannah (left to right).

On the 7th March 2009, Rebecca was 3 years old. She has a long list of problems associated with her rare disorder including low muscle tone, poor balance, fine and gross motor delay, global developmental delay, visual impairment. Proprioception, sensory problems and depth perception problems mean she becomes very distressed and screams. She also has self-injurious tendencies.

Most importantly though, she is our sweet angel, and we love her with all our hearts. She has such a special smile she lights up the room.

However, without Karen and the wonderful service from Contact a Family directing and supporting us on so many occasions we would probably still be feeling alone and isolated. We cannot thank Karen enough for all the hope and support she has given to us. We all look forward to her visits and she always has time for my 3 daughters; they love to see her arrive.

Family support services



RARE CHROMOSOME DISORDER SUPPORT GROUP

Unique is a UK-based charity providing vital support and information on any rare chromosome disorders. Membership of Unique is free. Unique is keen to support new members from Northern Ireland. This organisation is a valuable source of information and support to families and individuals affected by any rare chromosome disorder, and to the professionals who

work with them. They offer a linking facility with other families with the same condition, have a member's forum and provide specific disorder information days throughout the year.

For new membership applications, please go to the www.rarechromo.org/html/HowToJoinUs.asp and follow the instructions.

For all other enquiries contact:

Unique
The Rare Chromosome Disorder
Support Group
P.O.Box 2189,
Caterham,
Surrey CR3 5GN, England

Telephone or Fax: 01883 330766
Email at info@rarechromo.org or
rarechromo@aol.com



CBIT is a UK-wide charity offering support to anyone affected by childhood brain injury which has happened after birth. Acquired brain injury isn't something families prepare for. The Child Brain Injury Trust responds to the needs of those families in the following ways:

Child and family support

We provide emotional support, information and social opportunities for children and families affected by an acquired brain injury. This can be in the hospital or at home and we

also support children and young people in school to ensure they are receiving the correct support.

Training

CBIT offers training for health and education professionals working with young people with an acquired brain injury.

Information

CBIT has a wide range of information on acquired brain injury including publications for children, young people and families. CBIT operates a helpline (0845 6014939) and a website

(www.cbituk.org) both of which offer ready access to information.

Raising awareness

CBIT works to make people more aware of the issues surrounding childhood acquired brain injury so that families are able to access the support they need and live life to the full within their communities.

If you would like more information about CBIT in Northern Ireland you can get in touch with one of the two Child and Family Support Officers in Northern Ireland, Gillian Allen or Karen Donaghey, on 028 9081 7145

Resources and publications

New guidance to help young people with learning disabilities plan their future

The Foundation for People with Learning Disabilities has published a new workbook for young people with learning disabilities to help them plan their future after school or college, as well as an information booklet for their parents. The easy read workbook, *My kind of a future*, covers a range of topics including staying healthy, getting around and getting ready for work. *My kind of a future* was developed to encourage young people to plan their own lives independently and think about their future.

Prepared for the future? has been written specifically for parents, siblings and other family members wanting to help a young relative lead a fulfilling life after leaving school. The booklet covers a range of topics in jargon-free language, including: getting support, opportunities available, moving from the family home, health and getting support in your caring role.

Both *My kind of a future* and *Prepared for the future?* can be downloaded for free from: www.learningdisabilities.org.uk/

Recognising fathers survey

The Foundation for People with Learning Disabilities has also published a national survey of fathers who have children with learning disabilities. The report argues that current policies and practices often fail to acknowledge or support fathers in their roles as carers.

The findings have implications for education, health and social care practitioners and policy makers for children with disabilities. They are also relevant to employers and health workers, such as GPs, who have a role to play in supporting fathers as carers.

Recognising Fathers: A national survey of fathers who have children with learning disabilities describes how many fathers want to be more involved in the raising and caring of their offspring. More than 90% felt their involvement had a positive impact on their child's development. Yet policies and practices in health and social care, as well as employment, do not always acknowledge a father's caring responsibilities, focusing primarily on mothers as carers. This often leads to fathers struggling to combine their caring roles with employment, and to stress-related illness.

The research adds to the evidence that the involvement of fathers improves the lives of children with disabilities.

View the free downloadable survey at www.learningdisabilities.org.uk/publications/?entryid5=32902

NEW! Podcasts from Contact a Family

New podcast on Proximal Focal Femoral Deficiency

Proximal Focal Femoral Deficiency is an uncommon condition which occurs before a baby is born. The condition affects the bones in the lower limbs including the hip, knee and thigh bones.

This podcast is a mother's experience of having a son with the condition.

New podcast on Pitt Hopkins syndrome - diagnosis

A mother and father discuss their experience of the process of diagnosis for their child with Pitt Hopkins syndrome. Pitt Hopkins is a rare genetic condition characterised by severe learning disability, breathing abnormalities and characteristic facial features.

Listen to these and other useful podcasts at www.cafamily.org.uk/news/podcasts.html

Best of You Tube!

Contact a Family have 3 new web videos. The first is about the organisation and the services provided, the second is about the benefits of parent to parent contact *Meet the Parents* and the

final one features two fathers of children with disabilities in *Meet the fathers*.

They can be viewed by going to www.youtube.com/user/cafamily

Do you see me?

The Early Development Network (EDN) provides services for children from birth through to age three who are not developing typically or who have been

diagnosed with a health condition that will affect their development.

www.youtube.com/watch?v=fu6YPYxmD8

New! Information on medicines for children

A new range of information leaflets for parents and carers has been launched. The project aims to provide appropriate and accurate information about medicine dosages, side effects and general advice to those giving medicines to infants, children and young people in their care. A number of leaflets have been produced on a range of topics including pain and epilepsy. The development of the leaflets was driven by demand from parents, and parent support groups were involved at every stage.

At present there are leaflets for about 25 medicines and work is underway to develop more. The current range can be viewed and downloaded from www.medicinesforchildren.org.uk

Free information sheets and DVDs

The Challenging Behaviour Foundation has a range of free downloadable information sheets covering: getting a statement, pica, specialist equipment and safety interventions. They also have five DVDs available to view online. Parents have found these very informative:

- "light at the end of what has been a very dark tunnel"

- "has given me courage"
- "very positive and easy to watch"

Topics covered include challenging and self-injurious behaviour. The DVDs cost £31.50 each, but are free of charge to parents and unpaid carers.

www.thecbf.org.uk
email info@thecbf.org.uk
or telephone 01634 838739



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

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