

contact a family
for families with disabled children

incorporating
The Lady Hoare Trust

in **contact**



The newsletter of Contact a Family North East

www.cafamily.org.uk/northeast

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Special iApps

Pictured left are County Durham parents Bev and Colin Dean with son William using the Special Words app that they have recently developed for the iPad
(Photo by Keith Taylor)
See page 4 for full details

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Contact a Family would like to thank Northern Rock Foundation for their continued support of the North East Office

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northern rock
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Contact a Family News

The new SEN National Advice Service

Contact a Family is delighted to announce that we have been awarded the Department for Education contract to include a Special Educational Needs advisory service within our existing range of services for families.

The new SEN National Advice Service will be part of our integrated Helpline/Online service for families. It will be staffed by experienced SEN advisers. It will be a one stop shop for parents and other family members caring for a child with SEN, on all education issues.

The telephone helpline will enable parents and carers to get one-to-one, in-depth and personalised advice from fully-trained SEN advisers.

We will also offer online services for more general advice and guidance, via email, our website, facebook and twitter to enable families to engage with us and with each other.

Our SEN service will cover comprehensive advice on a broad range of issues related to special educational needs in any education setting, including:

- Early years/portage
- School Action and Action Plus
- Individual Education Plans (IEPs)
- Statutory Assessments
- Statements
- Transition Planning
- 139A assessments and post-16 provision
- Home education
- Bullying
- Exclusions
- School transport
- 16–19 Bursary Fund

To contact the helpline telephone **0808 808 3555** or email **helpline@cafamily.org.uk**

The helpline is open Monday to Friday 9.30am-5pm.

Contact a Family North East 0191 213 6300

Contact a Family News

Stronger Families, Happier Lives

This new Contact a Family fundraising appeal was recently launched by Samantha Cameron who visited our office in Lewisham, London in October 2011.

The aim of this campaign is to raise money to enable our continued work as well as raise awareness of the issues facing families of disabled children in the UK today. The money raised from the campaign, will go towards broadening and strengthening our current services to ensure that we can support the increasing number of families with disabled children who are coming to us for help during these tough times.

For further information about the campaign, please visit

www.cafamily.org.uk/getinvolved/ourappeal

The Cumulative Effect – The impact of welfare reforms on families with disabled children now and for future generations

Contact a Family is planning to highlight in the media the potentially harmful cumulative impact of the welfare reforms on families with disabled children. We are concerned that government proposals to halve disability additions under the Universal Credit as well as reforms of tax credits, council tax and housing benefit will have a snowball effect on many households. We are looking for families with a disabled child or children aged under 16, willing to talk to the media about their situation who fall into one or more of the following categories:

- Getting child tax credits and has a disabled child whose DLA does not include the high rate for personal care.
- The parent/s are on a low income or don't work.
- Live in private rented accommodation and have their housing benefit restricted under the Local Housing Allowance rules.
- Have experienced a reduction in the amount of support they receive for childcare, through the working tax credits.
- Couples where only one partner is employed and they work between 16 and 23 hours a week.
- Live in council/housing association accommodation and have a child whose disability means they cannot share a bedroom with a brother or sister.

If you would like to tell your story, please get in touch with our media team:

elaine.bennett@cafamily.org.uk and michele.cefai@cafamily.org.uk

Contact a Family North East 0191 213 6300

Special iApps

As featured on the front cover of “In Contact”, a new piece of educational software developed by County Durham parents is helping to make learning easier for children around the world. Special Words, a picture and word-matching educational app designed for young children, launched recently and has already sold in 25 countries.

The software was developed by Bev and Colin Dean, who live in Durham and whose son William has Down Syndrome and other special educational needs. “We got the original idea after a chance meeting with one of the parents on the Making Changes Together group in Durham who suggested getting an Apple iPad to help William’s learning,” explained Bev. “We looked into it only to find that the various apps which already existed weren’t suitable or easy for young children to use”.

Over the following months Bev and Colin developed and perfected Special Words, with help from William and his older brother Joseph aged 12 and using feedback from other families involved in the Making Changes Together group. Now Bev and Colin have set up a not-for-profit social enterprise company, called Special iApps, and recently they launched their first app, Special Words, which is available for people to buy from the App Store website. Their next app, Special Stories, an app for creating simple stories using words, pictures and sound, will be available soon.

The couple have received support from a number of organisations, including Down Syndrome Education International, The Education Centre for Children with Down Syndrome, The Sol Curry Charitable Trust, Down’s Syndrome North East, UnLtd – an organisation set up to promote social entrepreneurship – and DLA Piper through the UnLtd Connect Network.

Proceeds from the sale of Special Words will be used in the development of further apps and to support charities which work with children with special educational needs. People can find out more by visiting www.specialiapps.co.uk

So how can you get an iPad?

Contact a Family produces a list of charities that give grants to families who have children with disabilities and additional needs, some of which may be able to help fund equipment such as iPads for your child. If you would like a copy of this list, please get in touch at northeast.office@cafamily.org.uk or call us on **0191 213 6300**

Contact a Family North East 0191 213 6300

Gen'd Up - Feedback

Feedback from workshop: 'Gen'd Up? Children & Young People's Experiences of Genetics' held at: Great North Museum, Newcastle upon Tyne

Researchers from the Policy, Ethics and Life Sciences Research Centre, Newcastle University recently brought together parents/carers, geneticists, and other relevant professionals to discuss findings from a 3 year in-depth research project which explored experiences for families whose child had been referred to paediatric genetic services. The workshop focussed on the experiences of the children and their siblings. The aim was to generate discussion with those present on points raised by the children and young people, and consider ways forward for families and service providers.

Children and young people were encouraged to come along too, and had the choice of being involved in the discussion, or be part of the fun provided by Sensory Spaces child care team. Perhaps not surprisingly, most opted for the fun!

The research team presented an overview of issues raised by children and young people in the study. These included ways in which they think about genetics and about health, and often have questions about the future, both in terms of possible medical advances and risk to potential future children. Participants then took part in mixed discussion groups - facilitated by representatives from Contact a Family and Unique - to consider the main challenges around supporting children and young people over the time of genetic investigations.

The very lively discussion highlighted a number of areas, including: how initial referral to genetics can feel like entering a world of the unknown, and that additional information at this time would be very helpful; it is useful to acknowledge in consultations what everyone's expectations are, and what diagnosis may provide and may not provide; there are pros and cons to the availability of a wide range of information on the internet; children are also accessing the internet, although not necessarily to investigate their condition; and, children and young people (those referred and their siblings) need additional support to deal with the many uncertainties.

The overall consensus on the day was that systems and processes have generally improved around genetics and genetics services, but that more still needs to be done to support children and young people, and the people close to them. For further information about the study, please see the website at

<http://www.ncl.ac.uk/peals/research/project/2745>

Contact a Family North East 0191 213 6300

Local Information

What is Pass It On?

Pass It On is a group of Newcastle parents and carers who acknowledge that they all have a responsibility to pass on information to each other and to Families Information Service (FIS). Pass It On is a network of connected families, workers and agencies.



The group aims to get good relevant information out to families of children with disabilities and special needs in Newcastle and to support families to help each other and stay in the know. They will do this by:

- Developing a network of Pass it On Parents
- Encouraging and committing paid workers to sign up to being a Pass It On Worker and sharing information including their own details with FIS as an identified information channel
- Writing and sharing information for families by families
- Developing and raising the quality of services within the city used by families of disabled children, by encouraging and developing an honest feedback mechanism
- Assisting and directing the FIS to keep families of disabled children in the know

The group's next meetings are 6 January, 3 February and 2 March 2012 all from 9.30am– 1.00pm held in room 300 Civic Centre, Newcastle (tea/coffee provided) For more information you can contact them through either the Families Information Service on **0191 277 4133** or the Parent Carer Participation Officer **0191 277 4605**; on Facebook: Search groups "Pass It On Newcastle" or email **Passitonparents@gmail.com**

New Fragile X Support Group County Durham

This new group is open to parent/carers of children and adults with a diagnosis of Fragile X Syndrome. They meet on the last Wednesday of every month from 1.30pm to 3.30pm at Leadgate Childrens Centre, Consett, County Durham. They regularly have guest speakers at the group and also organise family days out, normally one Sunday approximately every two months.

For more information, please contact Sarah Smith on **07588037485** or email **sasinfinland@hotmail.com**

Contact a Family North East 0191 213 6300

Local Information

How can Mencap support your family?

A Mencap Personal Assistant - someone who, although employed and managed by Mencap, works with a family to offer them a range of support and through **Short Break Care** which is designed to provide both a break for carers and families and an important opportunity for children to socialise and learn new skills.

Why choose Mencap?

Flexibility: Support can be in the family home, out in the community or on a family holiday. **Reliability:** They provide support that can be relied upon **Person-centred:** Every child is different, they will help you to choose the right person to support your child. Your child will have their own personal support plan helping them to develop according to their needs, goals and ambitions. **Stress free:** Mencap deals with practical issues such as pay, training, CRB checks and professional supervision. **High quality:** They have an outstanding record of providing high-quality care, and are constantly striving to develop and maintain these standards. **Training:** All Mencap staff have a comprehensive induction and receive continued specialist training to enable them to provide the best support.

Mencap predominantly works with people with a learning disability, however, their person-centred approach enables them to support people with other disabilities and/or diagnoses. They have experience in supporting people with physical disabilities, autism and mental health issues. You can access their support with a personal budget or other form of direct payment, or by paying with private funds.

How can you find out more?

To find out more about how they can help your family please call Mencap Direct on **0300 333 1111**, visit www.mencapdirect.org.uk or email them at mencapdirect@mencap.org.uk

Mixed Emotions Support Group

This support group is for parents with a child/children with hidden disabilities. (Dyslexia, Dyspraxia, ADHD, Autism Spectrum). They meet on a Friday each fortnight from 7.30-9.00pm at Lesbury Village Hall, Lesbury, Alnwick (including school holidays). Cost is £1.50 to cover the cost of the hall.

For more information, please contact Fiona Shell on **01665 833781** or email fionashell@btinternet.com

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Makaton Workshop

Makaton Taster Workshop - Stockton

In conjunction with Cerebra and Stockton United for Change, we have organised another Makaton Taster workshop which will take place on **Thursday 12th January 2012** from 10.30am to 2.00pm (including lunch) at the George Hardwick Foundation. The workshop will be delivered by Shona Chambers from Cerebra; is free and open to parent/carers only. Help towards travel and childcare costs is also available.

This fun and interactive session gives parents the opportunity to learn approximately 30 signs and symbols and provides the chance to discuss ideas on how you could use Makaton with your child at home. Numbers are limited and available on a first come, first served basis so if you would like to book a place, please contact us on **0191 213 6300** or drop us an email at **northeast.office@cafamily.org.uk**

Contact a Family North East & Cumbria Local Contacts

Family Support Worker for Cumbria

Debbie Armstrong is our Family Support Worker in Cumbria. Debbie can provide one to one support & help with lots of information about local services etc. You can contact her on **01228 550069** or by email at **debbie.armstrong@cafamily.org.uk**

National Freephone Number - 0808 808 3555

Contact a Family's **National Freephone Helpline** for parents of disabled children is open from Monday to Friday 9.30 a.m. to 5.00 p.m.

The text phone number is **0808 808 3556** and Language Line is available for parents whose first language is not English

If you did not receive this newsletter at your own address and would like to be added to our mailing list, please give us a call or write to us at Contact a Family, The Dene Centre, Castle Farm Road, Gosforth, Newcastle upon Tyne NE3 1PH.

Tel/Fax - 0191 213 6300

E-mail - northeast.office@cafamily.org.uk Website - www.cafamily.org.uk/northeast

The next edition of **In Contact** will be circulated **Spring 2012**

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