

contact a family
for families with disabled children

incorporating
The Lady Hoare Trust

in contact

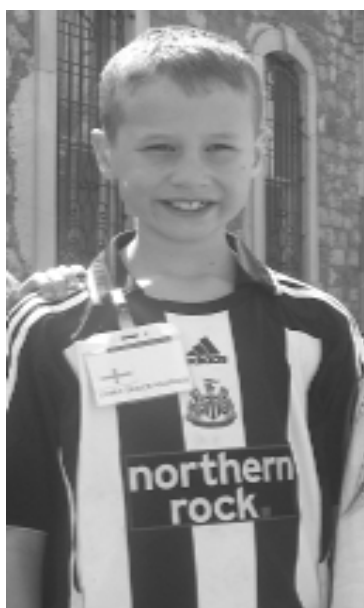


The newsletter of Contact a Family North East

www.cafamily.org.uk/northeast

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Tyneside to Turkey!

Pictured left is Laurie Ambrose Taylor aged 10 from North Tyneside.

See Page 4 for the story of his journey and his fantastic achievement

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



Contact a Family News

We are celebrating our 30th anniversary in 2009! For the last three decades, we have been strengthening families with disabled children across the UK by providing advice and information and putting them in touch with others whose child has the same condition for support.



We have also campaigned for better rights for families, but the campaign goes on. The number of disabled children has risen significantly since the 1970s due to medical advances and increased diagnosis and reporting – between 1975 and 2002 the disabled child population rose 62% whilst the general population increased by just 7%. And while there have been changes in the support services and entitlements for families with disabled children, there is still much to do to ensure families can lead the lives they choose. So our work continues to be as vital now as it was 30 years ago.

To coincide with our anniversary, Contact a Family recently published new research based on a survey completed by families on our website. **What Makes My Family Stronger** highlights how families still feel stigmatised and shut out from society. The survey was completed by 615 families and found negative attitudes towards disability, coupled with a lack of services are the main barriers preventing families with disabled children from leading ordinary lives.

Key findings of the 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.

To read the full report, please visit <http://www.cafamily.org.uk/pdfs/wmmfs.pdf>

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Local Participation News

As part of the Government's agenda for disabled children and their families, Aiming High for Disabled Children Parent Participation grants have been given out in two Phases. Phase 1 Grants have now been fully spent by all but one area in the North East – so huge congratulations to all involved for all your hard work and creative thinking.

Each grant of £3,300 in Phase 1 was designed to support parents to come together to look at how they could collectively influence the way services are provided for disabled children in their area. Lessons were learned! Some people thought £3,300 was not enough and then had trouble spending it all. Other people thought it was to be spent on the children (no!); even more people thought they could keep it in the bank account for a rainy day (again, no!). But mostly parents and carers worked really hard to make sure all the great ideas they have had festering were listened to and turned into reality! Phase 2 money is now on its way - £10,000 for each area.

The money is there to ensure that parents have their own independent means to support any local parental involvement. Most local authority areas have collaborated with parents to hold large conferences and meetings to gather parents' views and feed them into local planning. In this next Phase we are asking how parents who are not currently involved are being invited to contribute. Some people like to receive information about local plans while others like to actively take part, with the view that they are improving services for other families and their disabled children, particularly children who aren't born yet.

Parents across the North East and now in Cumbria are becoming part of this massive change by sharing their experiences and suggesting practical ideas that professional workers can move forward – parents tell me they are seeing real changes happening for their family; new ideas about short breaks and information sharing that are making a practical difference for them and their kids. Pictured left are parents from County Durham and Cumbria who met recently to learn from each other and share what has been happening in their own areas.



We're not out of the woods yet, but, on a good day we can just about see the light through the leaves. Whatever your family situation, parents in your area will need your help to move forward. Come on - get stuck in!

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Laurie's Story

Tyneside to Turkey

"I'm going to Turkey", our son Laurie announced one day when he returned home from school. This wasn't quite the case we discovered, once we'd checked the letter from school. It stated that four pupils from Laurie's class would be chosen to go on a week long exchange to a school in Turkey, and we needed to give permission for his name to go forward. We didn't hesitate to do this, partly thinking that he wouldn't be selected as it would be too much like hard work taking a 10-year old boy with autism on an exchange trip like this. We filled in the form, but said to Laurie that he may not be chosen as there would be other children in his class who would want to go, and he accepted this.

It came as a very happy surprise when the school Head phoned to check if we were happy for Laurie to go as he had been selected. Laurie attends Waterville Primary School in North Shields and has a place in their Communication Resource Base, but is now fully included in class with support. I did question the Head about whether Laurie was selected because they felt they should, as part of inclusion, but he reassured me that Laurie was selected using the same criteria as used for the other children.

So, just after the Easter holidays, Laurie and three other children went with staff to Bartin near the Black Sea (a seven-hour coach journey from Istanbul Airport). The theme of the exchange was sport, and as Laurie loves football he was happy to get involved with trying out new sports as well as playing as much football as possible with the Turkish boys. In fact, one of the photos from school showed the other children enjoying an ice cream while Laurie was off playing football!

As Diane Rodgerson, the teacher in charge of the exchange said:

"Laurie was a credit to himself, his family and his school. He fully interacted with the foreign children not only from Turkey but from our other partner schools from Ireland and Hungary as well. He coped admirably with the lack of routine; a new country and culture; new food and even learned some phrases of a new language. The staff and children had a wonderful time and we are grateful to the funding from The British Council and Comenius which gives children from our school, including Laurie, the opportunity to interact with children from other cultures through sport, which as this project proves, is truly an international language"

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More Story & Directory Info

Laurie came home completely shattered after a very long coach and plane journey, but having had a fantastic time. He dealt with meeting new people, eating different food, and absence of routine, all in his stride. We are so proud of him and this great achievement. When we look back to the days when, as a small boy, Laurie had very little speech, would have tantrums if he was prevented from doing what he wanted to do, or was taken out of his routine. And now, we have a ten-year old boy able to successfully participate in such a school exchange trip, coping with new experiences and handling things appropriately.

We hope by sharing this story we show how valuable it can be to give our children plenty of opportunities and challenges, and how they can surprise us all and shine.

Jackie Ambrose & Adam Taylor

Contact a Family 2009 Directory - Out Now

The Contact a Family Directory is the UK's leading guide to disabilities and health conditions, including rare disorders. If you work with children or adults affected by disability or additional needs, the Directory is a vital resource for you and your colleagues. The Directory is available in paperback for £40, or as an annual subscription to an online version for £17.25. Order the book now, and you can also get the online subscription at a reduced price of only £5, helping you to have all the information at your fingertips and the click of a button.

The paperback book also comes with a free wallchart (while stocks last) detailing benefits, practical help and support available for families with disabled children.

To order the Contact a Family Directory, visit our website at :

<http://www.cafamily.org.uk/shop.html?scat=8>

New ways to get in touch on makingcontact.org

Contact a Family's flagship social networking site now has message boards to enable families with children with rare conditions across the world to share experiences and support each other. There are over 6,000 parents registered on our on-line service MakingContact.org. Parents can make contact with others whose children have the same condition in order to gain, and give, support through the sharing of experiences and knowledge. For more information visit

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

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Local News

Heel & Toe

As previously featured in a recent edition of In Contact, Heel & Toe is a registered charity helping children in the North East with Cerebral Palsy, Dyslexia or other motor impairments. They are Ofsted registered and have recently received an Investing in Children award. They currently have places and sessions available.

They aim to provide therapy and a learning process called Conductive Education to children aged from birth to 16 years old. The aims are on improving children's mobility, independence and motor skills, whilst building their confidence.

The centre is in Spennymoor, County Durham and any child in the North East can access the service which is open from Monday to Saturday 9.30am to 5.30pm. If any parent or carer is interested in obtaining more information, please contact them on **0844 3350512**, email **info@heelandtoe.org.uk** or visit the website at **www.heelandtoe.org.uk**

Doing something for Charity??

Two brave women are training to trek the Great Wall of China for Tiny Lives, a charity that cares for families who have lost little ones. Shirley Brown and her sister Gail Flannery are fundraising like mad with BBQs, Fancy Dress Parties and other events to raise the money for their 2010 trek and their charity – if you would like to know more or even donate, please contact them at Shirley's email address which is **shirley.brown@thepensionservice.gsi.gov.uk**

Please don't forget that Contact a Family is a charity too and we have lots of various ways you could help us out – sponsored parachute jumping, gift aid donations and maybe doing the Great North Run? You don't have to go to the other side of the Earth to help us out – we'll still appreciate it!

National Autistic Society help! Programme in Hartlepool

Running for six sessions during September & October 2009 at Owton Manor Baptist Church, Hartlepool. this free programme is for parents/carers of children aged between 5 and 11 years and who have received a diagnosis of an autism spectrum disorder (ASD) within the last 18 months. The programme sessions cover a range of issues for families. Places will be allocated on a first come, first basis. For a booking form contact Wendy l'Anson on **07747 020269**

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Local News

Sunderland, Washington & Coalfields Parent & Carer Council (PCC)

The PCC was set up late 2007, after the annual Parent Carer Forum after parents were inspired at a workshop by Katie Clark from the Calderdale Parent Carer Council. They held their first meeting in November that year, and are going from strength to strength. In 2008, they were asked to chair the annual Parent Carer Forum in Sunderland. The group is run entirely by parent carers - all volunteering their time. They are working in close partnership with many professionals throughout Sunderland, and have taken part in many consultations.

Many of the parents now also sit on various planning/strategic boards and steering groups. They hope in the future to be a central point for parent carers and be able to direct parents to condition specific support groups as well. In summer 2008, the PCC received lottery funding of just under £3,000 to help with set-up and running costs. The Co-Op also donated £100 to purchase supplies for a series of coffee mornings that were held in November 2008.

Some of the aims of the PCC are:

- 1) To provide support and information to parents and carers of children and young people with special educational/additional needs, and/or a disability.
- 2) To listen to the views of the families, children and young people, and work with them to enhance, and make a difference to, their lives.
- 3) To promote good working relationships, communications, involvement and transparency between themselves and the families, children and young people.
- 4) To involve, where practical, the families, children and young people in workforce development.

The PCC try and meet every month, to discuss what's happened over the last month, and what their next steps are. Everyone is welcome at these meetings and they often have service providers popping in. The PCC also works very closely with Sunderland Carers Centre and have worked together on the recent employment of two Parent Participation Workers. For more information or to join the PCC, please see their website at <http://www.freewebs.com/swcpcc> e-mail them at swcpcc@googlemail.com or give them a call on **0191 4175322**

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The Keppleway Project

Keppleway challenges exclusion and is founded on a commitment to bring disabled and non-disabled people together as equal partners, promoting the ethos of inclusion. The Project operates a fully accessible and inclusive education and outdoor activity centre in the English Lake District, offering adventure, challenge, learning and relaxation for all. Keppleway also provides consultancy and training in: disability awareness issues, complying with legislation and good practice, to the statutory, voluntary and business sectors.

The Project is holding an open day on **Saturday 26th September 2009** and would like to offer families, disability organisations and special schools the opportunity to enjoy leisure together; try some of the on-site activities, see the fully accessible facilities and talk to their experienced staff.

Please contact them for further details:

The Keppleway Project, Broughton-in-Furness, Cumbria. LA20 6HE

Tel: **01229 716 936**. Visit their website at **www.keppleway.org.uk** or email them at **stay@keppleway.org.uk**

Contact a Family North East Volunteer Parent Representative

Bob Mitchell is in Northumberland and is happy to help local parents and professionals who would like more information about Contact a Family. You can contact him on **07532450218** or by email at **bob.mitchell@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 10.00 a.m. to 4.00 p.m. (& 5.30 - 7.30 p.m. Monday)

The textphone 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 **Autumn 2009**

The views and suggestions in **In Contact** are those of individual contributors and are not necessarily supported by Contact a Family.

Contact a Family cannot accept responsibility for any goods or services mentioned in or enclosed in **In Contact**

Summertime 09



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for families with disabled children

Fun in the Sun!
Summer 2009

Hi Everyone, here's hoping for the good weather they've been promising us this Summer. In this insert, you will find details of local leisure ideas that we hope you are able to take part in. Have a lovely summer.

Jamboree Sensory Spaces Project

Jamboree is a group of parents, performers and disabled artists who aim to provide multi-sensory creative experiences for children with multiple and complex needs.

Their sensory spaces bring the wonders of the sea to disabled children and their friends - complete with sand, water and mythical creatures!

Come and listen to the sea or hear a song about you, feel pebbles and shells, and the sea-spray on your skin. Watch as stories unfold and discover hidden treasure.....

This year, the space can be found at the Ouseburn Festival in Newcastle on Sunday 19th July and on Thursday 23rd July it will be at the Alan Shearer Centre for the launch of the Newcastle/Gateshead National Autistic Branch. For more information, please see their website at www.freewebs.com/jamboreeproject or email them at jamboreeproject@yahoo.co.uk

If you know of any summer activities taking place for families, let us know at northeast.office@cafamily.org.uk and we will include them in our email bulletins.

Blue Teens Youth Centre

Blue Teens Youth Centre in partnership with Aiming High for Disabled Children in Sunderland are running a project to engage disabled young people in healthy physical activities. Disabled young people are invited to join the group in enjoying and experiencing the fun and achievement of participating in healthy activities such as cycling, fishing and visits to the cinema and museum.

Blue Teens Youth Group are keen to welcome new young people to join them, and are experienced at making activities accessible to young people with a range of disabilities. All activities are free to young people. For more information and to book places please contact Blue Watch direct on **0191 521 4060**.

North Tyneside Summer Family Fun Day

Cosmic Kids are holding a Family Fun Day on Monday 24th August 2009 at the Blue Flames Sporting Club exclusively for families living in North Tyneside with a child who has any additional needs. This free event will include bouncy castles, face painter, magic and balloon shows, ventriloquist and an animal show

Contact Lynn McManus on **0191 280 8163** for more information.

Middlesbrough Sportability Club

Children of all abilities aged 8 to 19 years of age are welcome to join the club for their mid week holiday programme at Holmwood Sports Hall, Middlesbrough. This will run on Wednesdays and Thursdays from 10.00 a.m. to 2.00 p.m. on 29th/30th July, 5th/6th August and 19th/20th August.

It costs only £2.00 a day and there lots of fun and games to take part in.

To book places, call Tom or Mick on **01642 832651** as soon as possible as places are limited.

Useful Vision

Useful Vision have some Summer Activities planned in the next few months including a Water & Sports Activity Day at Newburn Activity Centre and a Riding Day at Three Lane Ends Farm, Bishop Auckland.

These activities are for families registered with Useful Vision (registration is free and for North East families who have a child with a visual impairment)

To register or find out more information, see their website at www.usefulvision.org.uk or give them a call on **01434 682160**

Stockton Parent Support (SPS)

SPS have a range of activities running throughout the summer including dance/drama and sportability. For full details, please see their website at <http://www.stocktonps.co.uk/> or give them a call on **01642 878137**

The Boardroom

A local parent told us about The Boardroom as a great place her sons with ADHD and Asperger Syndrome really enjoying going to.



It's an indoor park built for BMX, skateboarding, inline skating and the teaching of circus skills, free running and break dancing. The people who run it are Ricoh and Rosa with a team of volunteers. They are dedicated, patient and very encouraging to all levels of skill.

You can see all their details on their website at <http://www.boardroomnewcastle.com/> or if you would like to speak to Ricoh or Rosa for more information, give them a call on **0191 2722882** or **07793045420**

Ability to Play

Ability to Play is a project that supports children with disabilities to reach their potential through sport. The service helps disabled children and young people with any level of sporting ability to access sporting opportunities organised across South East Northumberland.

If you would like more detail, contact Adam Dixon at Blyth Sports Centre, Bolam Park, Blyth NE24 5BT or telephone **01670 367286**