

contact a family
for families with disabled children

incorporating
The Lady Hoare Trust

in **contact**



The newsletter of Contact a Family North West

www.cafamily.org.uk/northwest

Issue 19 Summer 2005

Parents' Participation in improving services



The theme for this newsletter is participation, and the photo shows Francine Bates (our Chief Exec) and Liz Ranger (in her new role as Parent Participation Manager) launching the new "Making a Difference" resources. We have a report from our successful 'Listen Up' conference on the NSF (National Service Framework) on the middle pages and further information on participation on page six.

We also have another new member to our North West Team. Helen

Bourke is our new North of England Manager. She will be overseeing our office in the North West and the office in the North East as well as developments throughout the North region.

We are sorry to announce that Mary McBride, our Regional Development Officer, will be leaving us at the end of July and there's a message from her on page two. If any of you would like to come and say goodbye we are having 'open house' on Monday 18th July between 10 a.m. and 2 p.m. Just give us a quick call if you want to join us for nibbles and a chat.

Sharon (editor), Helen and Jo

Write or call **Helen, Jo or Sharon**
We'll phone you back.

Contact a Family North West
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The views and suggestions in this newsletter are those of individual contributors and not necessarily supported by Contact a Family. Contact a Family cannot accept responsibility for goods and services mentioned in this newsletter.

Supported by



News from our volunteer parent reps

Our Reps' contact numbers

Lancashire	Pat Fleming	01254 854604
St Helens	Ruth Card	01942 721323



Pat has recently decided to tackle the local Sports and Leisure Centres about their accessibility (or non-accessibility) to children and adults with complex needs. She's been giving feedback to her local Centre about changing facilities, hoists, general layout and access between different areas, so her son Tim and other young people can enjoy swimming and trampolining. She is feeding back to the FIND Database team and Sport for All. If anyone else is tackling these things in Lancashire, she'd be pleased to hear from you.

While working on St Helens Action Research Project (SHARP), Ruth decided to collect together all the information she had about appointments, assessments and admissions to hospital for her daughter to see how much time and effort had been spent by a child and family with disability. She then compared these figures with those for a more typical child. The total figures researched to date (covering seven years) are: actual contacts 774; hours spent on appointments and phone calls 4942; miles driven relating to assessments and admissions 11004. Since doing this research Ruth has been busy sharing these findings to show the importance of Multi-agency. She wrote an article for our national magazine, Share an Idea, has had an article published in the national Early Support Programme newsletter and she presented her findings at a recent Early Years conference in Cheshire.

Ruth says, "My conclusion is that families could have some of the added stress of their child having a disability removed if:

- ❖ Appointments were grouped together instead of spread over days and weeks
- ❖ The key worker system and co-ordination became the expected way of doing things
- ❖ The child is always seen as part of their family.

I believe that every family like mine could demonstrate similar effects if only they had the time to keep records."

Goodbye from Mary

After 12 years with Contact a Family, I'm going to be saying goodbye on 21st July. It's amazing how much has gone on in those years, and hard to remember it all - the parents and groups we've met and who have made Contact a Family so welcome, the information events and joint working with other voluntary organisations, numerous workshops around the region bringing parents together, and the individual parents we've spoken to on the phone, perhaps only once, but then we've kept in touch via this newsletter. More recently, as our work on involving parents in developing services has grown, that's given new links with some extraordinarily dynamic parents, plus enthusiastic and committed service providers - this has to pay off in improving services for children and families for the future. My current plans are to return to health visiting, so I'll be having more one to one contacts with families, but over a much smaller geographical area.

We're planning an open lunchtime 'drinks and nibbles' session here on Monday 18th July, so do give us a call if you can drop in and join us.

Thanks so much and best wishes to all of you. *Mary*

Contact a Family North West: 0161 743 0700

Local Groups page

Funding Workshop



We ran a workshop for parent groups in Manchester recently to assist them in accessing funding for their group. The day included: what grant givers ask for, sources of funding and fundraising Do's and Don'ts. More information about fundraising can be found at

<http://www.cafamily.org.uk/GAPFundraising.pdf>. For a group action pack go to <http://www.cafamily.org.uk/GAP.html>. We have also recently subscribed to the Charities Information Bureau's funding newsletter. If you run a parent group and would like us to send you this monthly bulletin by email, then please give Sharon a ring and she'll add you to the distribution list.

Directory of Social Change (DSC) Launches new websites

The Directory of Social Change has launched two new websites for people accessing information on grants, educational grants and company giving.

Look at www.trustfunding.org.uk or www.companygiving.org.uk for more information.

The Co-op Community Support Programme aims to encourage community involvement through supporting voluntary and community groups and organisations. Grants between £500 and £30,000 are available. Application deadlines are the 1st week in August and 1st week in November. For more information call 01706 202032 or visit www.united.coop/FoundationApply.asp.

Grants Website one stop shop Voluntary and community organisations can now access one site for government funding at www.governmentfunding.org.uk.

Oldham Community Learning Chest.

Grants are available to groups from £50 to £5000 and to individuals up to a maximum of £500 for local residents to learn the skills and knowledge they need to be able to play an active role in the regeneration of their communities. Call 0161 214 0951 for more information. The next deadline is 31 July. Community Chest grants are available in 21 of the 22 North West local authorities.

UnLtd Millennium Awards Scheme support people who want to develop their own skills and who want to make a positive change. They offer grants to individuals and informal groups throughout the UK. For more information call 01274 728 525 or visit www.unltd.org.uk.

The Local Network Fund is a government initiative set up to co-ordinate government policy and services for children and young people. Groups of parents can apply for between £250 and £7000 to run activities for disadvantaged children. To find out more information or to apply call 0845 113 0161 or look at <http://www.everychildmatters.gov.uk/strategy/localnetworkfund/>

BT Community Website Builder allows voluntary and community organisations to build and maintain their own website free of charge. Groups need a computer, an internet connection and a web browser. Visit <http://www.communitykit.co.uk>



Participation

'Listen Up' Parents' conference, Leeds, 14th May 2005 Using the NSF to influence services

The National Service Framework (NSF) is the government's ten-year plan to improve services for children. It applies to health and social services but also involves education services. The aim is to develop services which are based around the needs of children and their families instead of focussing on the needs of organisations delivering the services.

- The NSF is about participation
- The speakers were inspiring
- Very positive fun speeches, not all doom and gloom

Our conference in Leeds aimed to bring parents up to date with the NSF and how they can use it to influence services locally and nationally. It was also the launch of ***Making a Difference***, our guide for parent groups and leaflet for parents on using the NSF. Over 60 parents from around the country attended with many staying over the night before, giving an extra dimension to the networking opportunities! Here is a brief summary from the speakers.

Understanding how the NSF works

Parents have real power – use it well

Excellent networking

Christine Lenehan, Director of the Council for Disabled Children spoke about the changing environment for disabled children, including the increased recognition of Autism Spectrum Disorders and the rise in children with

complex needs, plus social changes such as an increased recognition of the rights of disabled people to an ordinary life and a move towards inclusion.



The Children's NSF is part of a wider shift in policy and legislation changing the culture and structure behind the provision of services for families with disabled children. It aims to break down the barriers and attitudes excluding children from mainstream services and to create a more open and positive atmosphere. It poses challenges for service providers in terms of staff time, skills and commitment, and reluctance on the part of some local authorities to learn from existing good practice, but also opportunities for parents to participate and influence services.

Building alliances with local service providers. Katie Clarke of Calderdale Parent and Carers Council described the building blocks of participation as individual parents. At the time the Calderdale Council started, the blocks were scattered - parents were angry with service providers, there were lone parents sitting on local authority working groups with no back up, the general feeling between parents and service providers was very adversarial and consultation was a joke.

Ideas from Katie about setting up groups and involving disabled young people



With the vision and practical assistance from Leicester Parent Carer Council, parents in Calderdale got together and started working together. They looked for allies amongst key service providers, focussed on partnership working and stressed the value of parent input.

As parents they needed information, and needed to separate their anger from their work with service providers, and the situation of their own child from that of local children in general.

They now have two part time workers, both parents, working term-time, plus an admin worker and have become Children's Fund "best value project". Parents set the priorities at parents meetings. Issues raised are taken up with service providers. Progress reports are circulated and the Council continues to grow with many projects in the pipeline.

Influencing policies at national and local level. Virginia Bovell spoke about the work of PACE (Parents Autism Campaign for Education). Established in 1998 in the context of national under provision of autism services, PACE has proactive and reactive in lobbying and in media work, thus raising its profile and influence. Practical issues for PACE have been around whether to work with others (on a general disability issue) or whether to lobby specifically on autism issues; and in relation to media work, the challenge of getting a message across without distortion.



Virginia made the point that there is often a gap between government policy and impact on the ground. When working to influence policies at local level, her tips are:

- ❖ check what national policy really is
- ❖ refer to national advice organisations (e.g. CDC, Contact a Family)
- ❖ feel indignant but keep calm!
- ❖ laugh
- ❖ remember the long term
- ❖ believe you are making a difference
- ❖ remember what the goal is

- Make sure you plan your strategy
- Ideas re national policy from Virginia
- Keep personal feelings separate

PACE will shortly be publishing a Parent's Handbook, giving parents the resources and tools to influence policy in their local area.

There was a choice of workshops in the afternoon which parents could attend.

Sharing experience, find another group who have done it.



Parent Participation Parent Participation



Parent participation is a key element in implementing developments in local services for families. In response to this we have some new publications that have been drawn up alongside the Council for Disabled Children and influenced by parents and professionals.

- **'Parent Participation – a Parents' guide'** supports parents who would like to be involved or are already involved in influencing services for disabled children.
- **'Parent Participation – Professionals' Guide'** covers the key principles involved in successful participation.
- **'Parent Participation – health settings'** is aimed at paediatricians and their colleagues as well as for parents who wish to work with them in influencing services provided for disabled children.
- **'Making a Difference – local parent groups'** looks at how parent groups can use the Children's National Service Framework (NSF) to influence local services.
- **'Making a Difference – the NSF and parents of disabled children'** is a leaflet showing how individual parents can use the NSF to change the way services for disabled children are delivered.



If you would like to order a copy of these booklets please call 0161 743 0700. If you require bulk copies please contact our head office (details on back page). There is a charge for the Professional's Guide, all the others are free. For the latest on influencing health services from Contact a Family visit www.cafamily.org.uk/influence.html

Lancashire County Council are looking for parents to be involved in the development of support services. They are looking for 15 parents to join in a new Parent Services Development Group, to monitor the service offered to parents of children with special educational needs. You need to be a parent of a child with SEN attending a Lancashire school, and interested in shaping services for parents in general. Meetings will be three times a year starting from the autumn term, at times and locations convenient for parents, with travel expenses provided. For more information contact Peter Schoonjans, SEN Customer Services Manager on 01772 532248 or email him at peter.schoonjans@ed.lancscc.gov.uk or Lancashire Parent Partnership on 0845 601 4284 or email lpp@lancashireparentpartnership.org.uk

Parent carers participation in Cheshire are running a day on 19 July 10.30-1.00pm where parents' can get involved in developing service in Cheshire. The day will include: What does participation mean?, How do parents get involved?, How do parents find out what's going on in Cheshire? It will take place at Holiday Inn Runcorn and lunch will be provided. To book a place call Melanie Theobald on 0151 201 3015.

Contact a Family North West: 0161 743 0700

Events



Nowgen is running a series of art workshops for members of genetic support groups, their families and those in some way affected by human genetics. There is a dance workshop on 2nd July, a poetry workshop on 6th August and a Textile workshop on 3rd September. For more information contact the artist in residence, Sayward Morley, on 0161 276 3213.

Henshaws Society for the Blind have lots of events coming up for children with visual impairments. For a full listing of events and further information please call Henshaws on 0161 872 1234 or e-mail info@hsbp.co.uk.

Early Intervention Conference

Thursday 29 September 2005, The Crown Hotel, Harrogate

£99 Professional £70.50 for Parents/Carers and individuals with ASD.

For further information contact the National Autistic Society on 0115 911 3367 or email conference@nas.org.uk

'Better Management of Challenging Behaviours'

Clayton Park Conference Centre, Accrington
6th September 2005 9.30 a.m. - 4.30 p.m.

This conference is for people who work or live with adults or children who have learning disabilities, autism spectrum disorders and other developmental disorders.

£30/£40 for parent members /non members.

For further information contact Action for ASD on 01282 412021 or email info@actionasd.org.uk.

Children's Seating Equipment

Liverpool Disabled Living Centre.

14th September 2005, 11.00 a.m. - 2.30 p.m.

For all children, parents and staff. As well as demonstrations for companies there will be independent advice from Liverpool Children's Community Occupational Therapy Team and Merseyside CALL (Communication Aids Lending Library)

For more information call 0151 298 2055 or email disabled.livingcentre@liverpool.gov.uk

Taking Care of the Carer: a recharge for mind and body

16 -18 September 2005 Chorley Lancashire

Includes: aromatherapy, reiki, emotional freedom technique and personal safety

This course is for unpaid carers.

£30 and includes all tuition, course materials, meals and accommodation.

For more information call 01257 516325 or e mail insight@ed.lancscc.gov.uk

'Sexuality and Personal Relationships'

Clayton Park Conference Centre, Accrington.

10th October 2005 9.30 a.m - 4.30 p.m. *This conference will be covering policies and practices that guide both learning disability*

and health services in terms of sexual behaviour and socio-sexual relationships.

£30/£40 for parent members /non members.

For further information contact Action for ASD on 01282 412021 or email info@actionasd.org.uk.

'Autism – a hands on approach' conference

is being held at the Pinewood Medical Education Centre, Stepping Hill Hospital, Stockport on 7th December 2005

9.15 a.m. - 4.30 p.m. This is the 2nd annual conference organised by professionals and parents in partnership.

The cost is £100 for professionals and £30 for parents. For more information contact Joanne Hewitt on 0161 275 5200 or

email Joanne.hewitt@man.ac.uk.

Contact a Family UK News

Updated factsheets

The Fathers factsheet has been updated. You can ring us for a copy or it can be downloaded from our website

<http://www.cafamily.org.uk/factsheets.html>

Contact a Family UK Office
209-211 City Road
London EC1V 1JN

Freephone Helpline
0808 808 3555
0808 808 3556 (textphone)
Monday to Friday 10 – 4
(Language Line available)

Access to dentistry

- ❖ Contact a Family is working with the British Dental Association to find out if there is a problem in accessing dentistry for disabled children. We will use the results of this research to try and improve services for families. We need to hear from families about their own experiences, good and bad, of finding NHS dentistry, finding a dentist who is sympathetic to the needs of families, struggling to pay for private care, getting physical access to a surgery - anything you like, connected to your experience of dental care for your child. If you have a moment to e-mail: helpline@cafamily.org.uk or drop us a line at Helpline (Dentistry Survey), Contact a Family, 209-211 City Road, London, EC1V 1JN. We'd love to hear from you by the end of July with your own experiences.
- ❖ There is also a stakeholder day "Improving access to dental care for people with special needs" in Warrington on 30th November being run by Halton PCT. For more details contact Nancy Moss on 077 89 00 6856 or email nancy.moss@nhs.net

Reaching out

Contact a Family is trying to encourage more parents to use our services and to promote the support that we can offer. One area that we are focussing on is working with black and minority ethnic families, fathers of disabled children and other groups that may not be using all of Contact a Family's services. If you are a parent and have experienced difficulties in accessing the helpline, Contact a Family information in general, or would like to make suggestions as to what sort of support or services you would most appreciate, we would really welcome your feedback. If you would prefer to chat in a language other than English, we do have access to an interpreting service. Please contact Matthew Henderson, Tel: 0808 808 3555 or e-mail: matthew.henderson@cafamily.org.uk

If you would like to be on our mailing list and receive this newsletter as well as details of our workshops, free of charge, please complete the form below and send to:

Contact a Family North West, 6th Floor, St James House,
Pendleton Way, Salford, M6 5FW. Fax: 0161 743 0711

I am a parent support group
 voluntary organisation statutory sector

Name:
Organisation:
Your post/title if you are a paid worker:

Address:

Post Code:

Telephone no:

Fax:

Email:



Fun Days Out with Animals

Whether your child likes donkeys or dolphins, Lions or Llamas – there is day out that's accessible, not too expensive, and most of all FUN! Please call the organisations listed before setting off to double check opening times and prices. These were correct at the time they went to press.

Chester Zoo is fully accessible for people with disabilities, there are disabled toilets and wheelchairs can be hired from £3.50. They have a loop system and guide dogs and hearing dogs are welcome. They also host free "Signing Weekends" with a BSL signer on site. Admission: £10.50 per child but the carer/parent goes in free. Chester Zoo has a Disability Advisor Mike Elkerton who can be contacted on 0151 201 5277 or you can call the general number on 01244 380 280.

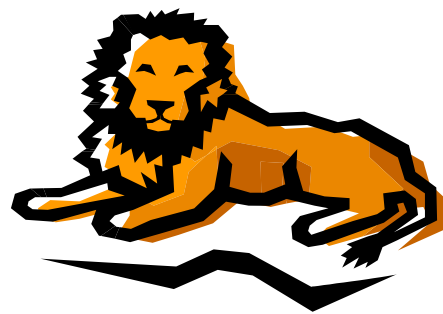
www.chesterzoo.org.uk

Blackpool Zoo is fully accessible and has disabled toilets. Wheelchairs are for hire for free but you need to book in advance. Admission: £4.50 per adult/child. Can organise a group rate by calling 01253 830805

www.blackpoolzoo.org.uk

Knowsley Safari Park has disabled access throughout. Admission: £6.50 per adult and £4.50 for under 16's Call 0151 430 9009.

www.knowsley.com

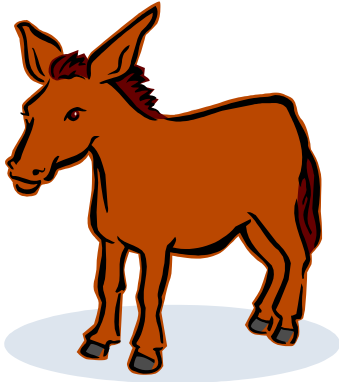


Martin Mere - The Wildfowl and Wetlands Trust, Burscough,
All areas are accessible including the hides and toilets. Free wheelchair loan, special parking area, Braille trail and loan of audio cassettes and players.



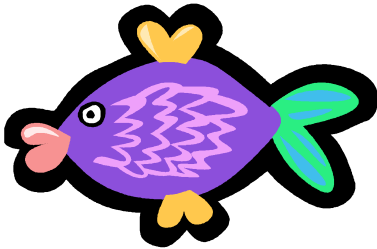
Admission: Adult £5.95, Child £3.75
Family Ticket £15.50
Call 01704 895181

www.wwt.org.uk



The Elizabeth Svendsen Trust for Children and Donkeys (EST), Abbey Hey, Manchester provides riding therapy with donkeys to children with special needs. It's suitable for children from 1 year old up to young adults. Riding skills are taught by qualified riding instructors using the donkey because of its placid nature. Children are also encouraged to groom and care for the donkeys. For more information and to arrange a visit call 0161 301 4051.

www.thedonkeysanctuary.org.uk/site/2/Home.html



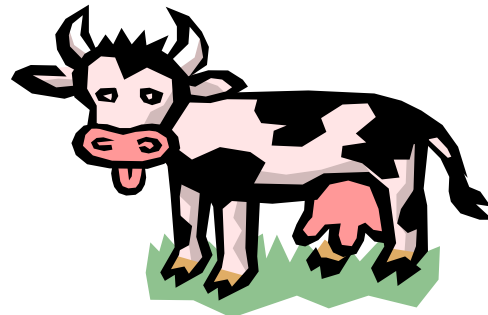
Sealife Centre, Blackpool has all forms of aquatic life to look at from shrimps to sharks. They have accessible lifts, and disabled toilets. The concession rate is £7.50 for a child but the carer goes in free of charge. This is an all weather attraction. For more information and to check the opening times call 01253 621 258.

www.sealifeeurope.com/uk/blackpool/home.htm

Acorn Venture Urban Farm, Kirkby, Merseyside is a 4 hectare urban farm, has a wide range of farm animals, a working goat dairy, and two children's play areas. The farm holds horse riding lessons for people with disabilities on Monday and Friday mornings. Pony rides are also available every afternoon during the summer holidays.

Admission: Adults £1, Children 50p, Under 3's free.

Call 0151 548 1524 for more information.



Lords House Farm Education Centre, Rishton, Lancashire is a Riding Therapy Centre for adults and children with special needs. There are 24 Horses and ponies, and an animal centre where farm and exotic animals live. For more information call 01254 877 400.

www.lordshousefarm.co.uk

If you have been on a day out to see animals and have enjoyed it, please let us know, and we can pass on the information to other parents. Call us on 0161 743 0700.