



**contact** a family  
for families with disabled children

# in **contact**

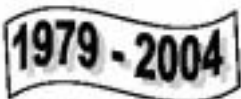
The newsletter of Contact a Family Wales

[www.cafamily.org.uk/wales](http://www.cafamily.org.uk/wales)



Ruth and Harri Jenkins at the Launch of the "Don't Push Me Around" Report  
(see page 4 for more information)

**Contact a Family Wales,**  
The Exchange Building, Mount Stuart Square, Cardiff, CF10 5EB, Tel. 029  
2049 8001, Fax 029 2049 5001 e-mail [wales@cafamily.org.uk](mailto:wales@cafamily.org.uk)  
UK Freephone Helpline 0808 808 3555



25 years of reaching  
out to families

**Summer 2006**

## Who to contact



### **Keith Bowen, Wales Manager**

- any matters relating to national policy and campaigning
- linking with other voluntary organisations
- training for professionals

**e-mail [keith.bowen@cafamily.org.uk](mailto:keith.bowen@cafamily.org.uk) tel. 029 2049 8001**



### **Katie Barrett-Goode, Enquiries and Group Development Officer**

- general or individual enquiries relating to a disabled child
- local group development
- factsheets and publications
- anything to do with the Contact a Family Wales newsletter or mailing list

**e-mail [katie.barrett-goode@cafamily.org.uk](mailto:katie.barrett-goode@cafamily.org.uk) tel. 029 2049 8001**



### **Martin Davies, Paediatric Project Officer**

- talks to health professionals
- supporting parents who would like to get involved in shaping child health care
- supporting health professionals who'd like to work in partnership with parents

**e-mail [martin.davies@cafamily.org.uk](mailto:martin.davies@cafamily.org.uk) tel. 029 2049 8001**



### **Jill Bartlett, Development Officer—Workshops & Events**

- workshops for parents
- family days
- events and activities

**e-mail [jill.bartlett@cafamily.org.uk](mailto:jill.bartlett@cafamily.org.uk) tel. 01248 670965**



### **Pat McCarthy, Development Officer—Parents' Voice Project**

- parent participation
- local policy and campaigning
- participation training for parents and professionals
- developing parent forums

**e-mail [pat.mccarthy@cafamily.org.uk](mailto:pat.mccarthy@cafamily.org.uk) tel. 01874 665757**

### **Volunteer Local Area Representatives**

Our Volunteers are all parents of disabled children are available to offer support and information within their local area.

Brian Williams *Gwynedd* 01766 770 355

Diane Earl *Conwy* 01492 549 013

Toni Bewley *Denbighshire* 01745 584 190

Jane Dodgeon *Ceredigion* 01239 811 066

Tracy Price *Merthyr Tydfil* 01685 350 095

*The views and suggestions in this newsletter 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 with this newsletter*

## Updates

### Parents and Paediatricians Together Project

Following the launch of our interim report on wheelchair services for children and young people on 13<sup>th</sup> June (see page 4 for full details), I'm now producing the full report which we will launch in September 2006. However, there have been plenty of other things to keep me busy.

At Bridgend, we have been working with a group of parents who want to use their experiences to influence local healthcare provision. A meeting with local healthcare providers has been organised for late June. Our programme of talks to health professionals and student health professionals continues. We have now started to involve parents in giving these talks and this has proved to be very successful.

The Royal College of Paediatrics and Child Health has invited Contact a Family to provide a lay member for its Welsh business committee.

The Assembly's Children and Young People's Specialised Services Project is still a major item on my work agenda. I now sit on the project steering group and we have agreed to distribute copies of standards documents to other voluntary organisations.

If you'd like more information on project activities in Wales, please get in touch (details opposite).

### Parents' Voice Project

Get in touch if you would like to discuss how the project can help you raise any issues you have either with your local authority or with the Wales Assembly Government. I can come along to your support group or wherever you meet and set up a focus group day. At this we discuss what your issues are and how you want to go about raising them. From this I can organise one of the training days that I have created which will be tailored to how you want to take the issue forward.

The *Campaigning Training* day is proving very popular with parents and carers and really helps to clarify the way forward.

The *Parent Participation* training days look at what it means to get involved in policy making and planning at any level.

I can *create a training day* especially for your group if you feel that would be best.

For more information please get in touch (details opposite)

### Workshops

The last few months have been busy with workshops taking place in Aberystwyth, Flint, Wrexham and Llandudno. We have covered various topics such as "Growing up and sexuality" which proved so popular we had to hold the event twice! Fun was also had at the Communication and Negotiation skills with plenty of opportunity to laugh whilst learning to communicate effectively.

The film showings are proving a big success with further showings having taken place in Galeri in North Wales, at Theatre y Mwldan in Cardigan and at Taliesin Arts Centre in Swansea.

During the Autumn we have some manual handling workshops, further Negotiation Skills days, Challenging Behaviour workshops in Cardiff and some Wills and Trusts workshops (venues to be arranged).

Last November we ran a wheelchair training event in Glanllyn, Bala. Thanks to the "Archbishop of Wales" fund we will be holding a similar event this year on Nov 11<sup>th</sup> and 12<sup>th</sup>. Please contact me if you would like more details (details opposite)

## “Don’t Push Me Around”



Harri meets Welsh  
Assembly minister  
Jane Davidson



Keith Bowen,  
Contact a Family  
Wales Manager



Harri prepares for his  
speech



Neera Sharma of  
Barnardo's.  
Co-author of report

On 13<sup>th</sup> June 2006, Barnardo's, Whizzkidz and Contact a Family held a joint event at the Welsh Assembly in Cardiff Bay with the Health Minister, Dr Brian Gibbons to highlight problems with Wheelchair services in Wales. Parents and disabled young people attended the launch of **“Don’t Push Me Around”**, the Barnardo's and Whizzkidz report on wheelchair services for children and young people in the UK along with Contact a Family Wales' interim report on services in Wales.

***The National Service Framework for Children, Young People and Maternity Services Wales (“Children’s NSF”)*** sets very specific targets for wheelchair services. Contact a Family Wales wanted to find out if the NSF has begun to improve services for children and young people, so we conducted a survey in spring 2006.

### **Our initial findings were:-**

Over 80% of families waited longer than the NSF target of 6 weeks for assessment.

Over 55% of families waited longer than the NSF target of 8 weeks for delivery.

A significant number of parents told us that they had waited for more than 12 months stated in the NSF, for reassessment. More than half of the respondents told us that their children's chairs were not regularly reviewed and maintained.

Our survey highlighted an acute need for training for both children and young people and their parents.

More than half of parents told us that they had not been offered a choice of wheelchair and accessories for their child and that the designs of wheelchairs are often more suited to older adults than to the needs of young people.

At the event, Harri Jenkins (10), who uses a wheelchair and his mother Ruth shared their experiences of wheelchair services. We would particularly like to thank, not only Harri and Ruth, but all the other parents and young people who attended (some of whom travelled down from North Wales for the day). We would also like to thank those parents who took the time to complete questionnaires and who have also agreed to take part in the media campaign and submit case studies.

**A full report will be published in September 2006. Please let us know if you'd like a copy.**

## Notice Board



### Classical Music Concert in aid of Bobath Childrens Therapy Centre

Based in Cardiff this Centre offers specialist therapy to children from all over Wales

who have Cerebral Palsy.

On 2nd July at 2.30pm Richard McMahon will be performing a piano recital at The Royal Welsh College of Music and Drama to raise money for Bobath.

If you would like to be in the audience you will need to pre-book a ticket from the box office on 029 2039 1391 or, for more information visit:

[www.justgiving.com/musiconasundayafternoon](http://www.justgiving.com/musiconasundayafternoon)

You can also find out more about the work of Bobath at [www.bobathwales.org](http://www.bobathwales.org)

### RSVP Cars for Carers

Following the success of the Cars for Carers scheme in Pembrokeshire, RSVP (the Retired & Senior Volunteer Programme) is delighted to announce that funding has been secured from the Lottery to establish the scheme in Ceredigion. Designed specifically with unpaid carers in mind, Cars for Carers' volunteer drivers will be able to offer three journeys a week to the anyone who look after family members or friends at home.

If you are an unpaid carer in Ceredigion and need transport, Rachel Evans, RSVP project worker, would love to hear from you; the scheme will be in development over the summer and Rachel would like to start hearing from potential service users now. In addition, if anyone would like to drive for the scheme (mileage and sundry expenses paid), please contact Rachel for a chat to find out how you can help.

Contact Rachel Evans on: 07733 265 769



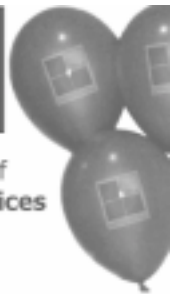
### Linkline to Welsh

The Link Line to Welsh is a unique service providing general information on Wales and the Welsh language. Specifically, the Link Line translates up to 30 words, edits up to 75 words, provides information on all aspects of Wales and the Welsh language, advises on place names in Wales. All of the above is free of charge. Link Line to Welsh tel: 0845 6076070, or email [cyswllt@bwrdd-yr-iaith.org.uk](mailto:cyswllt@bwrdd-yr-iaith.org.uk)

SNAP Cymru  
ANNUAL CONFERENCE 2006



Celebrating 20 Years of  
Parent Partnership Services  
in Wales



**MONDAY SEPTEMBER 18<sup>TH</sup> 2006**  
**9.20 a.m. - 4.00 p.m**  
**The Village Hotel Coryton, Cardiff**

### DISCIPLINE with DIGNITY *A Practical Approach* with Dr. Bill Rogers

If you need an inspirational day Bill is not to be missed. He is renowned for his practical effective and common sense approaches in dealing with behaviour problems in classrooms. Bill will present strategies which are easy to adopt and accessible for everyone to use. Everyone working with children and young people, including parents should attend.

Fees are as follows

**Residential Conference—£190** Dinner on 17<sup>th</sup> - Overnight Accommodation plus Conference on 18<sup>th</sup>

**Non-residential—£150** Dinner on 17<sup>th</sup> plus Conference on 18<sup>th</sup>

**Day Conference—£120** on 18<sup>th</sup> Only

Delegates Fee

**Bursaries available for parents, carers and young people**

For more information or to book a place contact Jenny Jones on 02920 388776 or email [jenny.jones@snapcymru.org](mailto:jenny.jones@snapcymru.org)

## Notice Board

### Second Space—Holidays

Second Space is a charity that organises holidays for parents who are carers of severely disabled or terminally ill children. People with second homes and holiday homes around the country donate one week a year to Second Space. In turn, Second Space offers these weeks to parents so that they might benefit from a respite holiday with or without their child, depending on their circumstances.

Second Space is in its third year; since the start of the scheme, it has managed to arrange around 70 holidays for families that care for an ill or severely disabled child. Second Space appreciates that a break or at least a change of scene can make an enormous difference, empowering parents so that they can continue with their caring duties.

The scheme has been a huge success and we are in the process of building up a database of families who might be interested in a Second Space holiday for the future.

Interested families should contact Second Space directly for an application form:

**Amanda Sidwell**

tel: 020 7792 9043

e-mail: [amandasidwell@secondspace.net](mailto:amandasidwell@secondspace.net)

web: [www.secondspace.net](http://www.secondspace.net)

### New Helpline Service for Children and Young People with Learning Disabilities

Respond have launched this new helpline service aimed at children and young people with learning disabilities who experience bullying, abuse, relationship or sexual problems, or who need simply to talk a problem through. Calls are taken by trained counsellors and a signposting service to other useful organisations is available.

**Helpline: 0808 808 0700** (Mondays and Thursdays 2pm-7pm; Tuesday, Wednesdays and Fridays 12pm-5pm)



### Hoppits—Swansea

This is a project which is run by Discovery student volunteering. The project works with people with disabilities in Swansea and is run specifically for those between the ages of 11 and 18.



The aim of Hoppits is to enable young people to participate in activities which they may not normally be open to. Hoppits is a project that takes teenagers with a range of disabilities on day trips, socials and residential weekends.

If you are interested or would like some more details please contact **01792 513186**

### Free Cinema Tickets

Cinema Exhibitors Association (CEA) in association with cinema companies and the Disability Rights Commission have introduced a new initiative - an ID card for those guests wishing to take advantage of our free ticket policy for carers. All major cinema chains in the UK accept this card.

The national concessionary "CEA Card" is now available and entitles the holder to one free ticket for a person accompanying them to the cinema. To apply for the card, the holder will need to meet one or more of the following criteria:

- Be in receipt of disability living allowance
- Be a registered blind person
- Be a holder of a disabled person's rail card

For further information, please contact:

The Card Network

**Tel: 0845 123 1292**

**Minicom / Textphone:**

**0151 356 7113**

[www.ceacard.co.uk](http://www.ceacard.co.uk)

[www.uci.co.uk](http://www.uci.co.uk)



## Notice Board

### The Denbighshire and Conwy Autism Support Group

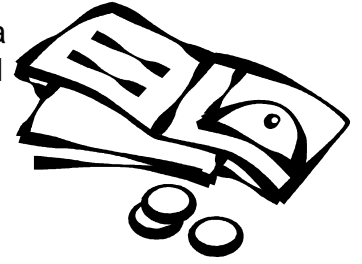
This is a new group open to all families in Conwy and Denbighshire who may have an autistic child (it's also open to autistic adults).

Meetings are held once a month, giving parents the opportunity to have a coffee and a chat. The group have good links with the Child and Adolescent Mental Health Services from which a Clinical Psychologist attends most meetings. A worker from SNAP also attends to meet with parents.

As well as the parent group held once a month, this group aims to hold separate activity days for the whole family. The next one of these is a "Party in the Park" to be held on 16th July 2006 in Eirias Park, Colwyn Bay.

For more information on this group or to find out about there up and coming events please contact **Dave Morgan on 01745 332686**

**CATCH UP Ltd** is a registered charity funded by Carmarthenshire Local Authority. They provide information and advice regarding welfare benefits, help people to complete benefit forms and advise them on challenging decisions they may not be happy with. Often people are not sure if they are getting the benefits they are entitled to and, providing they have relevant information from the client they can work out their entitlement. They also have a home visiting service for clients who are unable to get to the officer and a sections specifically for appeal tribunal advice and representation.



For more information on this service you can visit **[www.catchupltd.co.uk](http://www.catchupltd.co.uk)** or contact **CATCH UP** on **01554 776850** or email **[info@catchupltd.co.uk](mailto:info@catchupltd.co.uk)**



Are you aged 11 – 25, living in Powys and got something to say? Then enter the competition below.

### Have UR say and Win an iPod

The Children and Young People's Partnership (CYPPP) is carrying out an audit of need for children and young people in Powys. We want to identify the issues important to Young People and assess whether public authorities are meeting their needs. To do this we are looking at the delivery and accessibility of Services in Powys, in order to identify gaps in provision.

We want to find out what Young People in Powys want and don't want, if you are able to access services when you want to and if services are meeting your needs. The Children and Young People's Partnership is looking at all services in Powys from Education, Social and Recreational Facilities and Information Services to Transport Facilities.

The results of this Audit will allow us to plan for future services, and enable us to focus finances into sustaining and creating services that are either failing or are missing

To get involved with the audit and have your say visit [www.powysYOB.com](http://www.powysYOB.com) to complete a simple questionnaire, and you'll be in with a chance to win 1 of 3 iPods we are giving away.

The closing date is midnight July 31<sup>st</sup> 06, a draw will take place shortly afterwards and the 3 iPod winners will be notified in August. For a paper copy call 01597 82 6352.

Professionals and families are also invited to participate in the consultation by contacting us on the No. above.

**This is YOUR CHANCE to have YOUR SAY**

# Order Form

Please complete and return this form if you would like to order any of the Contact a Family Factsheets, or, if you would like to be on the mailing list for the Contact a Family Wales Newsletter.

I am:  Parent  Voluntary Organisation  Other (please state)

Parent Support Group  Statutory Sector .....

Name ..... Organisation (if applicable) .....

Address .....

Post Code ..... Tel No. ....

Please state quantity of factsheets required (any number of factsheets are free to parents although for others, additional copies are charged at 25p each unless otherwise stated)

I would like to be on your mailing list and receive ..... copies of the CaF Wales Newsletter

	Copies
When your child has additional needs <b>(£1.00 per additional copy)</b>	
When your child has additional needs (on tape) <b>(£1.50 per additional copy)</b>	
Benefits, Tax Credits and other financial assistance	
The Tax Credits Guide	
Caring for children with disabilities and special needs – A guide for students and professional workers	
Holidays Play and Leisure	
Living without a diagnosis	
Transition	
Siblings	
Special Educational Needs – Wales	
Grandparents	
Fathers	
A Genetic Condition in the Family	
Moving Into Work	
Aids Equipment and Adaptations	
Specific disorders and your child's behaviour—A Parent's guide to behavioural phenotypes	
Relationships and caring for a disabled child	
Assessments in England and Wales	
Dealing with debt –England and Wales	
The NHS and caring for a disabled child	

**A number of Welsh language factsheets Welsh are available on our website [www.cafamily.org.uk/wales](http://www.cafamily.org.uk/wales)**

**Please return this form to Contact a Family Wales, The Exchange Building, Mount Stuart Square, Cardiff, CF10 5EB Fax 029 2049 5001**

**Alternatively you could ring us on 029 2049 8001 or email [katie.barrett-goode@cafamily.org.uk](mailto:katie.barrett-goode@cafamily.org.uk)**