



contact a family
for families with disabled children

in **contact**

The newsletter of Contact a Family Wales

www.cafamily.org.uk/wales



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Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Summer 2008

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 tel. 01792 390203



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 tel. 029 2039 6624



Jill Bartlett, Development Officer & Family Support Worker

- workshops for parents
- family days
- events and activities
- individual support to families in North Wales

e-mail jill.bartlett@cafamily.org.uk tel. 01248 670965

Welcome Srabani

Contact a Family recently appointed Srabani Sen as our new Chief Executive. Srabani was formerly the Chief Executive for Alcohol Concern and has a wealth of experience in the voluntary sector.

Srabani said "I'm thrilled to be working at Contact a Family. It is a great organisation which has achieved much success since its inception due to the hard work, energy and commitment of staff. I am looking forward to seeing it through to its next stage of development"

Volunteer Local Area Representatives

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

Diane Earl *Conwy* 01492 549 013
Toni Bewley *Denbighshire* c/o 029 2039 6624
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

Contact a Family News

Help other parents of disabled children deal with bullying

Contact a Family is joining forces with Parentline Plus to produce a guide for parents of disabled children to help them cope if their child is being bullied and we're looking for your help.

Research suggests that more than one in three disabled children have been bullied at school and many parents can feel they have nowhere to turn. Bullying can take place at school, on school transport, in playgrounds, at leisure activities, online; bullying can take place anywhere.

The guide will be a tool for parents to help them cope if their child is being bullied. As well as containing information about the action schools should be taking and the legislation around bullying, it will include parents' experiences.

If your child has been bullied or is being bullied because of their disability and you'd like to share your experiences to help other parents please get in touch. We want to know how you spotted signs of bullying, the strategies you used to deal with the bullying, whether they worked or not, how you coped with the situation and any advice you would like to give to other parents in similar situations. Your experiences will be used anonymously in the guide.

If you would like to share your experiences or have any questions about the project, please contact Penny Roper on the freephone helpline 0808 808 3555 or email penny.roper@cafamily.org.uk. We look forward to hearing from you.

Newsletter by email

If you are interested in receiving this newsletter and other Contact a Family mailouts electronically, via e-mail please send an email from your chosen address with the subject heading "EMAIL NEWSLETTER" to katie.barrett-goode@cafamily.org.uk
It would also be helpful if you noted the current postal address that the newsletter goes to in order that we can replace it with you email address..

Counting the costs – Contact a Family survey

Finances can be a major concern for families with disabled children. It costs almost £7,000 a year more to raise a disabled child due to direct costs such as special aids and adaptations, transport, heating and childcare. With rising living costs affecting all families, Contact a Family wants to find out the effects on families caring for children with disabilities, serious health conditions or rare conditions living in the UK. This research will be used in future campaigning work. Please take the time to fill out our short online survey at

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

New Publications

Getting direct payments for your disabled child (England and Wales)

looks at direct payments, how to claim them and how they work in practice.

Money when your child reaches 16 years of age

looks at how benefits are affected when your child turns 16, whether you will be better off continuing to claim benefits for you child as part of your family or if they claim for themselves as an adult. It also outlines the main benefits available to young disabled children.

Your Views Count—Disabled Facilities Grant (DFG)

Contact a Family, in conjunction with Shelter Cymru and the Family Information Group will shortly be undertaking some research into DFG's.

We will be asking about your experiences of the DFG.

Do you know about the DFG?
Does it make a difference?
What works and what doesn't work?
How could it be improved?

You will shortly be receiving a questionnaire regarding this. **In the meantime, if you would like more information please contact Peter Mackie on 029 2055 6120 or email research@sheltercymru.org.uk**

Contact a Family Workshops

This Spring has seen a series of Workshops going on throughout Wales.

Growing up and sexuality has been the main topic of training this season with workshops being held in Barry, Cardiff, Anglesey and Monmouthshire.

We try and deal with what can be a difficult subject by offering suggestions and ideas. We have limited the number of parents at these workshops to 15 due to the nature of the subject and to give everyone a chance to talk. Families gain a lot of information while also having quite a good laugh!

Some **sleep workshops** were organised in conjunction with Cerebra and held in North Wales whilst the sleep workshop in Newport was unfortunately postponed until **September 17th**.

Three free **film showings** have taken place in North and South Wales -these events prove popular and, not only does it provide a good opportunity for children to enjoy a film but also for parents to chat over a cuppa.

We held some **Makaton** training in Conwy covering stages 1-4 with the follow on series being held early November (see cover photo).

Autumn Workshops

- | | | |
|--------------------------------------|------------|--------------------------------|
| • Sleep workshop | Newport | September 17th |
| • Growing up and sexuality | Pontypridd | Thursday 23rd October |
| • Growing up and sexuality | Cardiff | date and venue to be confirmed |
| • Wills and trusts | Cardiff | date and venue to be confirmed |
| • Free film showing | Conwy | date to be confirmed |
| • Makaton training stages 5-8 | Conwy | 3rd and 4th Nov |
| • Annual wheelchair training weekend | Gwynedd | Nov 14th -16th |
| • Free film showing | Gwynedd | date to be confirmed |

For more information on any of the above events contact Jill Bartlett

01248 670965 or e-mail jill.bartlett@cafamily.org.uk

PLEASE NOTE A SMALL REFUNDABLE DEPOSIT IS REQUIRED TO SECURE A PLACE ON ALL OF THE WORKSHOPS/EVENTS

Family Support Work

Thanks to funding from the Morgan Foundation, Jill continues to provide Family Support work in the three counties of Anglesey, Conwy and Gwynedd.

This service provides an enquiry or home visiting service for families of disabled children aged 0-19 yrs. This service is also confidential and free to families.

The work undertaken varies from dealing with housing associations to dealing with DLA forms with no one request ever the same! Families can refer themselves to the service or, agencies are also welcome to pick up the phone with any questions they may have.

For more information, contact Jill (details inside the front cover)

The
Morgan
Foundation
"making a difference"

Notice Board

Does a caring role have an effect on carers well-being?

Last year, North Wales readers of "In Contact" were invited, by Brenda Lewis, to take part in a MSc research study. The research looked at the caring role and whether this has an effect on the carers well-being.

Well-being scores were compared to a study of similarly aged individuals working in the manufacturing industry but not necessarily carers. Results showed carers having worse outcomes than the comparison group with regards to well-being. This was especially true for the female carers, with exhaustion and tension highlighted in the results.

One question asked carers to list things that would help their overall well-being, four themes emerged - support, financial, time and services. These are all practical things that could, and should, be considered as part of planning services to disabled children. The following quotes, taken directly from the responses, illustrate these themes.

Support

"Respite service when we want it, not make do with what is determined by others by lack of resources."

"Holiday clubs that run throughout holidays not for 1 or 2 weeks in summer for 1 or 2 days per week."

Financial

"more money, the cost of food for a child with special diet needs, and extra's really cut your budget"

Time

"I wish I could have time to relax"

"More individual time to spend with my child who does not have special needs"

Services

"Closer special schools, child has to attend school in another county".

"Suitable accommodation adaptations for my daughters needs."

Brenda would like to take this opportunity to thank all the people who gave up their precious time to provide this information.

NEWPORT GROUPS Parents for Change

This is a local Parents support group which concentrates on local campaigning as well as offering much needed support. **It meets the first Wednesday of the month at 10.30am-1pm at Bellvue Park Pavillion.**

SPLAT CLUB

Every Saturday, 10.30am-12.30pm

This group is an activity group run by members of Parents for Change. Splat Club offers an opportunity for parents to take their children along for a fun play session including, craft and music therapy. There is also an extensive lending library and Parents for Change members are always on hand to help and advise.

For more information on either of these groups please contact parentsforchange@hotmail.com or ring 07737 67824



www.netmums.com

Netmums is a free local website for mums. The best source of local information and advice is always other mums and Netmums now has more than 300,000 online members nationwide. So, you're guaranteed some great local information all recommended by mums!

- Indoors or outdoors play areas
- Baby and toddler groups
- Birthday party venues and ideas
- Family Friendly events, restaurants, farms and parks
- Childcare
- Working from home
- Nearly new
- Meet-a-mum

Netmums also offer advice and support on all those problems that life throws at you such as, postnatal depression, parenting issues and relationship worries. It also has a large section on raising a child with additional needs including lists of support groups in your local area.

Rough Guide to Accessible Britain

The first ever Rough Guide to Accessible Britain was published in April, with suggestions for disability-friendly places to visit in the UK.

The book covers city centres, parks and gardens and more unusual options such as wheelchair-accessible fairground rides and salmon fishing, while all attractions have been tried and tested by disabled researchers.

The guide costs £6.99, while blue badge holders can obtain a copy free (plus £1.99 postage) by calling 0800 953 7070. website www.accessibleguide.co.uk

Over the Wall

Do you know of a child with a serious illness who would benefit from a week of fun, new challenges and lifelong friendships?

OTW is a charity that provides residential camps for UK children and young people aged 8-17 years old who are affected by serious illness. It also provide weeks for brothers and sisters of young people with serious illnesses. These sessions offer the same opportunities to gain confidence and find support and understanding in new friendships.

Campers experience a variety of activities during the day, such as, archery, kayaking, climbing, horse riding, drama, talent shows, arts, crafts, technology and the media. There are also evening activities such as a disco, talent night and an opportunity to "camp-out" for a night with a campfire. All activities are supervised and take place in a safe, secure setting. The child's individual abilities are always taken into account.

Most importantly, all of this is free! Activities, food, accommodation and transport are provided free of charge.

This holiday scheme is open to any child or young person who:

- has been diagnosed with a serious physical or life threatening illness
- is under the care of a hospital consultant
- does not have to be on regular medication
- Is a sibling of a qualifying child

Unfortunately, OTW are unable to care for children with behavioural difficulties, autism, aspergers etc. They are also not able to take children with Cystic Fibrosis.

Core more information on these holidays, which are held in Dorset, Midlands and Perth please visit www.otw.org.uk or call 01420 82086

Cerebra Speech and Language Therapy (SLT) Voucher Scheme

Cerebra is running the scheme again in 2008 with new criteria:

To receive a Voucher, you will need to fill out an application.

Cerebra will only be accepting for children aged 16 and under who have a neurological, brain-related condition (For example cerebral palsy, autism, Down's syndrome) If they are school-age, the child must have an SEN Statement or be on School Action Plus in Wales and England, a Co-ordinated Support Plan in Scotland or be on Stage 4 or 5 in N. Ireland.

The child must not have received one on one speech therapy in the last 6 months.

A reference must be sent with the application. If your child is school age, the reference must come from the school. Otherwise it should be from a professional who works with your child (health professional, social worker, Portage worker.) The letter needs to confirm your child's condition and recommend speech therapy.

If successful, the voucher is worth up to £500 of SLT. Cerebra will be using speech and language therapists who are members of the Association of Speech and Language Therapists in Independent Practice (ASLTIP). All ASLTIP therapists are certified members of the Royal College of Speech and Language Therapists and registered with the Health Professions Council.

With the voucher, Cerebra will send a list of ASLTIP therapists in the family's geographical area. The parents will need to contact a therapist who is able to help their child. In rural areas of the UK one may find travel time and costs to see a private therapist impractical.

The therapist must invoice Cerebra direct for payment.

For more information or an application, please call Alex on 0800 328 1159 or e-mail alex@cerebra.org.uk.



Resolven Building Blocks Resolven Integrated Children's Centre

Resolven Integrated Children's Centre and Resolven Building Blocks aims to build the foundations of your family's futures within Resolven and the surrounding communities.

Resolven Integrated Children's Centre, is a purpose built, state of the art, not for profit, project, in the heart of the Resolven Community, to support parents & carers to return to employment or education, whilst offering the best opportunities for their children to explore their own potential in a safe, secure and stimulating environment.

Resolven Building Blocks' objective is to provide good quality affordable childcare and family services for the children and parents/guardians through providing a dedicated childcare and family centre.

Services Include:

- Early Years Centre
- Full Day Care, Including After School Club & Holiday Club (catering for children aged 0-12)
- Exceptionally Qualified Staff, over and above minimum requirements
- Adult Learning Programmes, from Short Course to Part Time Degree
- Extra Curricular Activities, Dance Classes, Exercise Groups, General Interests
- Community Support Services, Childcare Costs, Debt & Legal Advice Surgeries
- Partnership Working, Homestart, Parenting, Police, Glyn Neath Training Centre
- Community Café, informal meeting area with light refreshments & drinks

The centre also has a variety of office and conference space available to hire. This is as follows:-

Office Rental Space

Brand New Modern Office Space
Excellent Road Links
Affordable Cost
Excellent Facilities for Meetings, Conferences, linking into other Service Providers
A number of rooms Available to suit your needs
Fully Serviced with Internet and Telephone Exchanges

Conference, Meeting & Training Room Services

Brand New Light Airy Facilities
Number of Rooms Available to Suit Your Requirement
Rooms able to seat up to 100
Secretariat Services Available
Catering Coordinated to suit your needs

For more information about the centre, room hire or office space please contact 01639 711544 or email resolvenbuildingblocks@yahoo.co.uk

Tremorfa Coffee Group / We all Play Together, Cardiff

This group is for parents of pre-school children who have special needs.

It meets every Friday morning between 10-11am at Tremorfa Nursery school and is organised by SEN Health Visitor, Pippa Clark.

The aim of the group is to provide a supportive network for parents, access to specialist Health Visitor advice and to welcome parents into an inclusive mainstream nursery school environment.

Activities range from coffee mornings, 'stay and play' sessions, Language and Play, music group, aromatherapy and much more!

It's a very friendly, informal group that provides a great opportunity for children to play together while parents enjoy a coffee and a chat.

For more information, contact Pippa on 07966 194551

Do you know of a group or service that you would like to advertise?

We are always on the lookout for groups or services that would be of interest to parents from all over Wales. If you know of anything that would be relevant or have an article that you would like included in the next issue of In Contact please get in touch with

Katie Barrett-Goode on 029 20396624 or email katie.barrett-goode@cafamily.org.uk

Contact a Family Order Form

Name Organisation (if applicable)
 Address
 Post Code Tel No.
 Email

Any number of factsheets are free to parents although for others, additional copies are charged at 50p each unless otherwise stated

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

I would like to receive the newsletter electronically via email

Copies

When you child has additional needs (£1 per additional copy)	
Benefits and Tax Credits Information Pack (contains a number of factsheets)	
Family Information Pack - siblings - grandparents - fathers	
A Genetic Condition in the Family	
Understanding your child's behaviour	
Holidays Play and Leisure	
Living without a diagnosis	
Transition	
Special Educational Needs – Wales	
Education Maintenance Allowance	
The NHS and caring for a disabled child	
About families with disabled children	
Finding and paying for childcare	
Working and caring for a disabled child	
Aids Equipment and Adaptations	
Disabled Children's Services in England and Wales	
A guide to assessments and services in England and Wales	
Relationships and caring for a disabled child	
Dealing with debt –England and Wales	
The winter guide: help with fuel bills and keeping warm	
Money when your child reaches 16 years of age	
Getting Direct Payments for your disabled child (England and Wales)	
Sleeping	
Feeding and Eating	
Toilet/Potty Training	
Sex and Relationship Education for young people with physical disabilities: a booklet for teachers	
Growing up, sex and relationships: a booklet to support parents of young disabled people	
Growing up, sex and relationships: a booklet for young disabled people	
General Contact a Family Wales Information leaflets: workshops family support service etc.	
Information leaflet: Finding Medical Information on the Internet	

a number of welsh language factsheets are available on our website www.cafamily.org.uk/wales

Please return this form to Contact a Family Wales, 33-35 Cathedral Road, Cardiff, CF11 9HB Fax 029 2039 6625 or ring us on 029 2039 6624 or email katie.barrett-goode@cafamily.org.uk