

Winter 2009/10

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

# in contact

The Contact a Family newsletter

Wales

## Anniversary and *Our family, our future* celebrations

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### Contact a Family UK is 30 years old and Contact a Family Wales turns 10!

In November, we held a celebratory event at the Assembly where 30 photographs were displayed as part of the "Our Family, Our Future" report. This report has been produced to tie in with 30 years of Contact a Family is made up of stories and photographs of 30 families from across the UK whose children are affected by a range of disabilities to tell their story. We wanted to give parents a voice to talk about their achievements, acknowledge the challenges, reflect on their aspirations and fears for the future, and above all to celebrate their family life.



30 years of strengthening families with disabled children



### Local office

#### Contact a Family Wales

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Cardiff  
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Freephone helpline: 0808 808 3555

#### Welsh families featured in the report.



We would like to thank everybody who came along to join us in marking the achievement.

The report is available online at [www.cafamily.org.uk/pdfs/ourfamilyourfuture.pdf](http://www.cafamily.org.uk/pdfs/ourfamilyourfuture.pdf) or, if you would like a hard copy, please ring 029 2039 6624.

# Sign up to get our newsletter electronically

Get our newsletter by e-mail, stay up-to-date and help reduce our costs

Thank you to everyone who have already sent us your email address and are now getting the newsletter and other publications electronically.

We would like to encourage everybody who has access to email to do this and, therefore,

would be very grateful if you could get in touch with your email address.

Receiving the newsletter in this way will have no effect on the information you receive and you will still get notified of Contact a Family events and activities. As well as this, you will also receive updates between newsletters.

### Register now

Send an e-mail from your chosen address titled **"EMAIL NEWSLETTER"** to [katie.barrett-goode@cafamily.org.uk](mailto:katie.barrett-goode@cafamily.org.uk) In the body of the email, please state your **NAME, POSTAL ADDRESS** and the **COUNTY** you live in.

For more information on this service contact Katie, Tel: 029 2039 6624.

## 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: 01792 390 203



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

- General or individual enquiries relating to a disabled child.
- Local group development.
- Parent guides 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)  
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**Jill Bartlett**  
Development Officer and 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](mailto:jill.bartlett@cafamily.org.uk)  
Tel: 01248 670965

# Workshops, weekends and film showings

Our free film showings for families have been well attended and much appreciated by families' throughout Wales, writes Jill Bartlett.



We've held Film showings at Riverfront in Newport where we had an excellent turn out, a well attended event at Chapter in Cardiff and a similar event at the Arts Centre in Aberystwyth.

Ice Age three seems to have been a popular choice with many families attending the percussion workshop afterwards and spending time to chat over a cup of tea.

We still have film events coming up in the following locations:

Miford Haven, Torch Theatre on Saturday 6 Feb 2010

Mold, Theatre Clwyd on Saturday the 20 Feb @2.00 (note new time

and date) Caernarfon, Galeri on Sunday 7 March @1.30.

Please see the enclosed flyer for more details and booking information.

We would like to thank the venues for accommodating us and being so ready to help, particularly Chapter in Cardiff who have taken the idea on board and will be having regular film showings for families with disabled children. The first one of these took place in November and had a fantastic turn out. For more information on these showings, please visit [www.chapter.org](http://www.chapter.org)

My best wishes for the new year and I look forward to meeting some more new faces in 2010.

## Residential weekend

Along with the film showings, we held a successful residential weekend in Glanllyn with 54 people coming along to enjoy wheelchair training. We had an exceptionally wet weekend but it didn't dampen the spirits and we all had a good time.

Plans are underway for the next weekend in Llangranog on 26-28 March and, looking further ahead, a family weekend at Stackpole, Pembrokeshire in May. Please see the enclosed flyer for more information and feel free to give me a ring if you need more information. I will confirm places as and when I receive the refundable deposits. I'm sure this will be a popular event and I look forward to meeting new families then.

## Benefits and Epilepsy workshops

We still hold day time workshops and have held two on Benefits with another one planned for Pembrokeshire on 14 Jan. We are also planning an Epilepsy workshop on Anglesey on 20 January. Please contact me for further details.

## DCMW update

### Changing places campaigning success!

As well as making sure that all new Welsh Assembly Government buildings have a changing places toilet, the Welsh Assembly Government has committed to provide £225,000 to install new toilets in different places across Wales. The following nominations of suitable locations have been accepted:

- Pila Palas North Wales
- Llangollen International Eisteddfod grounds
- Oakwood Theme Park Pembrokeshire
- National Museum Of Wales Cardiff
- Museum of Welsh Life St Fagans

All nominations are now waiting approval from the Welsh Assembly Government. It is also hoped that if monies allow one may be sited at the Builth Wells Showground.

[www.changing-places.org](http://www.changing-places.org) contains the current and future intended locations of other changing places toilets in the UK. The Welsh Assembly Government have also funded a partnership between Mencap Cymru and the National Eisteddfod to make two portable changing place toilets available; These are ideal for making events accessible for all.

These toilets are designed to be easy to use for both carers and the disabled person, and include an electric hoist, height adjustable changing bench, peninsular toilet and plenty of space. The toilets are available on loan free of charge; only delivery and set up need to be paid for.

For details on how to book please call Alli on [01267 232256](tel:01267232256) ext 310 or email [wales.cpl@mencap.org.uk](mailto:wales.cpl@mencap.org.uk)

## Wheelchair Services Inquiry

Following the event we held at the Senedd in July, the National Assembly for Wales' Health, Wellbeing and Local Government Committee are holding an inquiry into Wheelchair Services in Wales.

On 25 November, Nicki Shercliff, a wheelchair user, and Michael Butterfield and Joanne Davies, parents of wheelchair users, went to the Senedd to tell the Committee how they feel about the services they receive. You can read

the evidence they gave or watch a recording online at [www.senedd.tv](http://www.senedd.tv)

You can also read or watch online the evidence given by the Disabled Children Matter Wales campaign on 18 November.

Read more on the Committee's website at: [www.assemblywales.org/bus-home/bus-committees](http://www.assemblywales.org/bus-home/bus-committees) if you have difficulty finding the information please get in touch with us and we can direct you to the relevant page.

## Launch of Early Support Wales

In September Early Support in Wales was launched at the Millennium Stadium, Cardiff. It was very well attended and offered participants a valuable opportunity to hear at first hand the potential impact that Early Support could have in Wales. It also gave participants the opportunity to start to consider what would be needed to ensure Early Support helps to improve services for young disabled children and their families. We would like to thank all of the parents who took part in the day, particularly those that sat on the parents panel and told their stories so well. It is essential that parents and carers are involved in making sure that Early Support happens in Wales. Without parents' and carers' involvement we cannot be confident that Early Support will do what it is supposed to do for families of young disabled children.

To find out more about Early Support in Wales, please visit [www.childreninwales.org.uk/areasofwork/disability/earllysupport/index.html](http://www.childreninwales.org.uk/areasofwork/disability/earllysupport/index.html) If you would like to receive updates on how Early Support is developing please sign up to the mailing list by contacting Kathy Beach at Kathryn. [beach@childreninwales.org.uk](mailto:beach@childreninwales.org.uk) or call [029 2034 2434](tel:02920342434).

## Network of key workers for families

CCNUK is a networking organisation promoting and supporting key working for disabled children and their families across the UK.

### What is key working?

Key working is a service, involving two or more agencies, that provides disabled children, young people and their families with a system whereby services from different agencies are co-ordinated. It encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels and a named key worker for the child and family. Families with disabled children should only have a key worker if they want one.

### What is a key worker?

A key worker provides a source of support for disabled children and young people and their families and a link by which other services are accessed and used effectively. Key workers have responsibility for working together with the family and professionals from services and for ensuring delivery of an inter-agency care plan for the child and family.

### Why key working?

Families caring for a disabled child or young person find that life is often a constant battle. Research over many years has shown that key working makes a huge difference. All the professionals working with the family work together. Meetings are focussed, with the family's needs at the centre. The key worker isn't the person who does everything. They are the person who makes sure everything gets done. CCNUK



believes that every family that needs a key worker should have one and we are actively campaigning to make this a reality.

Membership of CCNUK is absolutely free. Whether you are a parent /carer, disabled young person, professional or individual supporter, CCNUK needs membership from everybody who supports the model of key working and care co-ordination. Please visit our website at [www.ccnuk.org.uk](http://www.ccnuk.org.uk) to join.



However if you would like to become more involved, CCNUK Wales are looking for:

- 1 Parents of disabled children / young people with complex needs (aged 0-25 years) to serve on our Wales Group, which meets approximately 4 times a year in Rhayader, Powys between 10:30 and 14:00. We can offer you travel expenses if you do not live in either Cardiff or Wrexham (in which case we can offer you a lift). We are looking for someone who has experience of attending or chairing meetings as well as a knowledge of key working.
- 2 Parents of disabled children with complex needs (aged 0-5 years) to provide case studies for the Wales Early Support initiative. CCNUK is responsible for devising and delivering key worker training to key workers for 0-5 age range and would like to use these case studies in their training.

If you are interested in either serving on the Wales Group or in participating in a case study, please email either [sally.rees@ccnuk.org.uk](mailto:sally.rees@ccnuk.org.uk) (if you are based in North Wales) or [liz.walker@ccnuk.org.uk](mailto:liz.walker@ccnuk.org.uk) (if you are based in South Wales). We look forward to hearing from you.

## Travelling expenses

Did you know you can claim travel expenses for bus fare, train fare, petrol and occasionally, taxi fare if:

- You claim Income Support
- You claim (minimum Income Guarantee) Pension Credit
- You hold an NHS Tax Exemption Certificate
- You claim Working Tax Credit
- You claim Disabled Person's Tax Credit
- You claim Income Based Job Seekers Allowance
- You have an HC2 or HC3 Certificate

Fares can be paid for the patient only, if a patient travels on public transport and wishes to re-claim the fare of an escort, they must produce a doctor's letter to confirm that it was necessary to have an escort.

However, in the case of a child patient – fares are paid for the child and one adult only.

Travel expenses can only be paid for bringing your child to hospital and taking them home again, not for each visit. However, if you are in receipt of INCOME SUPPORT or MINIMUM INCOME GUARANTEE PENSION CREDIT and require help with visiting costs you can complete form SF300 so that you can be assessed for help from the social fund.

For more information on this you should contact your hospital's office or as the ward staff.

### Mencap Cymru: The Wales Learning Disability Helpline

This is a service which provides support and information on issues that affect people with a learning disability, their families and carers across Wales.

The service is made up of:

- A telephone or email helpline
- Regional Advisers
- A Welfare Benefits Adviser
- The Mencap website.

We will try and give you all the information you need to make the best decision for you. We can also give you details of other organisations that can help you.

The Regional Advisers can support you and give you information by phone, email, post, a direct visit, or a combination of these.

We cover all kinds of subjects, including campaigns, community care, benefits, education, employment, family and personal

relationships, housing, holidays, services etc. The Welfare Benefits Adviser can support you with understanding and claiming your benefits.

The service is for people with a learning disability, their families and those who support them, including professionals, or anyone who wants information on learning disability issues. We offer a bilingual service in Welsh and English, and use Language Line for other languages.

The telephone number is **0808 808 1111** and you can call us from 10am to 6pm from Monday to Friday, and from 10am to 4pm on weekends and bank holidays.

You can email us at [helpline.wales@mencap.org.uk](mailto:helpline.wales@mencap.org.uk)  
The website address is [www.mencap.org.uk/cymru](http://www.mencap.org.uk/cymru)

### AWCH Wales

This is a small charity, based in Swansea, that covers the whole of Wales. It is run purely by volunteers and was founded in 1962 by a group of parents and professionals concerned with lack of parental access to children in hospital.

As part of their service, AWCH have a small fund that is able to give limited help to families who

cannot afford to visit their child while in hospital, or take them to a hospital appointment. The fund is accessed through some hospital social work departments, or referral to AWCH by another professional.

For more information, please contact [www.awchwales.org.uk](http://www.awchwales.org.uk) or email [awchwales.org@tiscali.co.uk](mailto:awchwales.org@tiscali.co.uk) or ring (01792) 205227

### Rhondda Cynon Taf Carers Support Project

This project offers:

- Free A-Z Carers Guide and Information Leaflets
- Free Carers Counselling Service
- Free Training Days
- Free Information Events
- Opportunities for Involvement
- Referral to Benefits Advisers and other agencies

You are a carer if you look after a family member, a partner or a neighbour who needs your help because they are ill, frail or have a disability – and you aren't paid for the care you provide.

Contact us on Freephone CarersLine 0808 100 1801 Email [carerssupportproject@rctcbc.gov.uk](mailto:carerssupportproject@rctcbc.gov.uk)

## Student Nurse training

### We want your views!

I am a mum from Denbighshire who has a 19 year old daughter who is ventilator dependant and has spent the past 3 years in hospital trying to get a care package together so she can come home.

I am also a children's nurse lecturer at EdgeHill University. Part of my job is to coordinate the inclusion of service users into our nursing training.

I have been asked to try to find out what service users of ALL nursing services, children's, adults, learning disabilities, mental health and midwifery would like student

nurses and student midwives to have included in their training programmes. This is a great chance for us all to make a difference as the programmes for our university are getting rewritten in 2010.

I would be very grateful if you could all let me know what you feel is important for student nurses to know.

I can be contacted via email [bewleyt@edgehill.ac.uk](mailto:bewleyt@edgehill.ac.uk) or on 07734086655 or via the contact a family web page on Facebook.

Thanks, Toni

## Craig y Parc School for parents

School for Parents Service is a free service for families of children with cerebral palsy and other motor related disabilities. School for Parents is based near Cardiff at Craig y Parc School – an independent special school run by Scope.

The service aims to enable parents and other family members to gain a greater understanding of how cerebral palsy affects their child, to support the parent to learn how to carry out day to day activities with their child – play, self care etc, to help them to encourage their child to achieve greater independence,

to provide a network of support for parents and families and where appropriate provide guidance and support with the statutory assessment and statementing process.

The service aims to provide a comprehensive early years education that is appropriate to the age, ability and needs of the children and leads to the development of motor, communication, social and educational skills.

The service is based upon the practice and principles of Conductive Education and incorporates appropriate therapeutic input from

qualified paediatric physiotherapists, speech and language and occupational therapists. The aim is to provide a holistic play based service in conjunction with the key elements of the Early Years Foundation Stage Curriculum.

Alongside the education for the child we provide support and advice to their families and work with associated professionals to achieve the best possible outcome for each child.

For more information on the School for Parents please contact Ann Rhodes on 07974 837358.

# Contact a Family Wales order form

Name \_\_\_\_\_ Organisation (if applicable) \_\_\_\_\_

E-mail \_\_\_\_\_ County \_\_\_\_\_

I would like to receive the newsletter electronically via e-mail

Address \_\_\_\_\_

Post code \_\_\_\_\_ Tel No: \_\_\_\_\_

First copies of parent guide are all free although additional copies are charged at 50p each unless otherwise stated.

I would like to be on your mailing list

A number of welsh language parent guides are available on our website, Web: <http://www.cafamily.org.uk/wales>

When your child has additional needs (£1 per additional copy)	
Benefits and Tax Credits Information Pack (contains a number of guides)	
Family Information Pack – siblings – grandparents – fathers – relationships	
About Diagnosis (inc. developmental delay, behaviour, getting or living without a diagnosis, genetics and more)	
Holidays, Play and Leisure	
Preparing for adult life and 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	
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)	
A guide to dealing with bullying: for parents of disabled children	
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	
Checklist for parents – a simple explanation of help available to parents	

Please return this form to Contact a Family Wales, 33-35 Cathedral Road, Cardiff CF11 9HB, Tel: 029 2039 6624 or e-mail: [katie.barrett-goode@cafamily.org.uk](mailto:katie.barrett-goode@cafamily.org.uk)