

Spring Bulletin 2012

## Wales Support Group Survey

### Cefnogi Cynnar Early Support



***Are there enough parent support groups for families with young disabled children in Wales?***

***Do parents have enough opportunities to meet other families with disabled children in the early years?***

As part of the Early Support programme, Contact a Family Wales is undertaking a survey of parents' access to support groups across Wales.

Mainly concentrating on families with disabled children under 5 years of age, including those children with specific health or education needs. We would like to find out more about how many groups there are across Wales, how many parents can find a relevant group to attend, as well as what are the good and not so good things about taking part in a group.

We also want to hear from parents who do not attend any support groups to find out their experiences.

**We would like as many parents and professionals as possible to go on-line and let us know about what is happening in their area and what they think about parent groups for families with disabled children.**

To complete the survey please go to

<http://www.surveymonkey.com/s/DJ5FYP8>

Or for the welsh version please visit

<http://www.surveymonkey.com/s/JMJV3SS>

This information is protected by the Data Protection Act and will only be stored on our password secured computers and will not be passed on to anyone else without your expressed permission.

Or if you would prefer we can send you a paper version of the survey to complete in English or Welsh. **Email [wales.office@cafamily.org.uk](mailto:wales.office@cafamily.org.uk) or call 02920 396624**

If you would like know more about support groups or help setting one up please follow this link to the Contact a Family website for our group action pack where there is a series of publications to guide you through the different stages of setting up and running a group.

<http://www.cafamily.org.uk/families/supportinggroups/groupactionpack.html>

## Goodbye to Jill

After nine years working for Contact a Family Jill Bartlett has moved to work full time for NDCS.

Jill has been a vital part of the Contact a Family Wales team having organised hundreds of family days and events across Wales. As well as supporting individual families in North West Wales.

We would like to thank Jill for all her hard work and help to families over the last nine years.

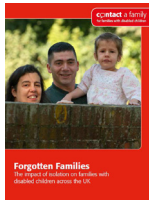
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## Contact a Family “Forgotten Families” Report 2011



A big thank you to all the families from Wales who took part in this survey. Over 1,100 families with disabled children across the UK (146 from Wales) responded.

**Two thirds of Welsh families with disabled children feel so isolated that it has caused anxiety, depression and breakdown.**

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*“For the first few years, I felt very isolated; we were forced to move into a rural council estate with no amenities as our original house was too damp. Me and her father split up when she was 18 months old. I would try to take her to parent toddler things but we just didn’t fit in as the gaps between her and her peers grew bigger. She was unable to sit unsupported so couldn’t be on the same level as other children.”*

Over two thirds (71%) of families with disabled children in Wales reported experiencing poor mental health such as anxiety, depression or breakdown. Almost half (48%) felt so unwell that they have asked their GP for medication or to see a counsellor.

- One in five (21%) say that isolation has led to a break up of their family or marriage
- Over half (56%) reported that the cause of their isolation is due to a lack of support from statutory services such as social services and the education system
- 54% say that not having the time or money to do things that other families do makes them feel isolated

- 57% said that they were not able to work as much as they would like to
- 50% feel that their isolation has been caused by the discrimination or stigma they have experienced.
- 60% felt most isolated when their child was first diagnosed
- 47% felt most isolated during school holidays.

### Contact a Family is calling on the Welsh Government to commit funding to:

- Continue the Early Support programme beyond March 2012.
- Implement section 25 of the Children and Young Persons Act 2008 to increase the duty on local authorities to provide short break services.
- Enable health bodies to implement the Carers Strategies (Wales) Measure to provide effective information and support to carers including parents with disabled children
- Ensure that parent carers have a voice and are partners in making decisions about services that help them lead a more ordinary and feel less isolated.

### Contact a Family is calling on the UK Government to:

- Commit to providing current levels of financial support through the disability additions via Universal Credit.

*“Sam is dependent on me to take him everywhere. This has become harder as he has got older as there are fewer places to go and no respite. This means that we have no time apart and my life and Sam’s life rolls into one.”*

You can view a copy of the UK Report and Nations insert at:

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

## Mencap “Inspire Me” Project



Mencap Cymru has a new project called “Inspired Me”. They are working with a group of young people from Ysgol Erw'r Delyn on a research project that will look into the accessibility of the shopping experience for people who use wheelchairs. For part of this research the young people have designed two online surveys.

The first is for people who use wheelchairs  
<http://kwiksurveys.com?u=erwdelynchair>  
it covers issues around the accessibility of shops, transport facilities and toilets. The Welsh language version is here  
<http://kwiksurveys.com?u=delyncym>

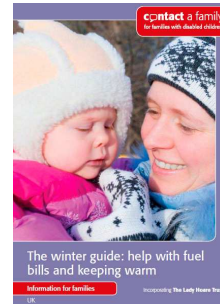
The second is for the parents of children who use wheelchairs  
<http://kwiksurveys.com?u=erwdelynparents>  
it covers similar ground to the first.  
The Welsh language version is here  
<http://kwiksurveys.com?u=erwrhieni>

The Inspire Me project is seeking to change the lives of 20,000 young people with a learning disability, their families and communities. The project is supported by The Co-operative Charity of the Year partnership. Young people with a learning disability are verbally abused, bullied, physically hurt, marginalised and left out of everyday life. Often they are unable to find a job, and are left with nothing to do.

If you need anymore information contact Paul Hunt by either email on

[Paul.Hunt@mencap.org.uk](mailto:Paul.Hunt@mencap.org.uk) or telephone on 02920 747588

## The Winter Guide: Help with Fuel Bills and keeping warm.



We have just released a new version of our popular publication “The Winter Guide”

This guide gives information about keeping fuel bills low, sources of financial help to pay bills and some practical suggestions around keeping warm in winter.

Some families with disabled children tell us of the difficulties of getting around outside the home and how it feels easier to stay in. You may have a child whose condition deteriorates in cold or wet weather.

In winter this means you may be using more fuel.

Everyone is worried about the costs of higher fuel bills and other related expenses like winter clothing.

Research also shows that one in seven parents of disabled children report inadequate heating in their home.

To order this publication or any other publications please fill in the publications order form attached to this newsletter or go to

<http://www.cafamily.org.uk/publications.html>  
where you can download a PDF copy

**If you would like any further help you can call our national helpline on 0808 808 355**

## Making the most of Technology

In a growing technological world there are now a wide variety of sites and applications designed for families with disabled children which can help in every day life.

### Getting started

Most people are now used to using 'search engines' such as Google to search for information. However you can't be sure of the accuracy of some of the information so be aware of the source of where it has come from.

For more on this go to

<http://www.cafamily.org.uk/medicalinformation/additionalmedicalinformation/>

### Other ways of accessing technology

In recent years there has been an explosion of forms of communication methods. These include apps (applications), Twitter feeds (useful links) and Facebook pages. Each one can provide you with different ways to help you.

### Apps:

These are applications that can be downloaded to a tablet computer such as an iPad or to a smart phone such as iPhone or the Samsung Galaxy. Many Apps are free and some will have a small charge to download them dependent on the owner of the app and size of the app. They can be educational, for example teach your child specific skills e.g. spelling and mathematics. Additionally, it can help you plan your child and your family's day e.g. hospital and social care appointments.

Although some apps are designed for specific purposes or disabilities they can often be helpful for people with a range of disabilities.

### Android:

#### ABCs app for Android

Alphabet flashcards combines letters, phonetics, and images to teach toddlers & preschool kids reading skills.

#### Autism at home app

Autism at Home provides ideas for creating learning spaces in the home for young children with developmental disabilities and autism.

#### Autism classroom app

This includes over 100 strategies for addressing 15 different common challenging behaviours

### IOS (iPhone and iPad):

These are just a few suggestions there many others out there to found and added all the time.

#### Going Places – for modelling social skills

**ABC Phonics** - Phonics application that targets letter sounds for the 20 letters of the alphabet and letter diagraphs. Children can trace letters to practice their letter formation.

**How's today** - tracker of behaviour for parent of children with ADHD

**Right pad** - handwriting to print

**Rxmindme** - a tablet reminder app- you input different medications and have different alerts for each whether it daily, weekly or monthly

### Twitter

Twitter is form of communication using short messages of up to 140 characters (i.e. numbers, letters, spaces, punctuation). These are called "tweets". It allows you to tell others about your experiences and interests as well the ability to follow other people.

Here are a few suggestions of Twitter feeds to follow:

Contact a Family

<http://twitter.com/#!/contactafamily>

Mencap Cymru <http://twitter.com/#!/MencapCymru>

SNAP Cymru <http://twitter.com/#!/SNAPcymru>

Autism Cymru <http://twitter.com/#!/AutismCymru>

Autism Puzzles <http://twitter.com/#!/AutismPuzzles>

NDCS Cymru [http://twitter.com/#!/NDCS\\_Cymru](http://twitter.com/#!/NDCS_Cymru)

### Facebook

Facebook is another useful way to connect with other people such as friends, other parents and organizations. It can also be used for discussions or have a virtual support group.

Here are a few suggestions of Facebook pages you could follow:

Contact a Family

<http://www.facebook.com/contactafamily>

Learning Disability Wales

<http://www.facebook.com/learningdisabilitywales>

National Autistic Society

<http://www.facebook.com/NASCymru>