



**Issue 2**  
July 2012

# the index

newsletter

The newsletter for children with special and particular needs in the Vale of Glamorgan



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# Hi All,

Since the re-introduction of the Disability Index in the Vale, we have received a total of 46 new referrals, of which nearly half have registered. Within the next few weeks I will be contacting all those currently registered on the index to update their details. We have also been busy promoting the index to other service providers and have had the launch featured in other providers newsletters to ensure we are reaching as many children as possible.

The Family Information Service has developed a series of web pages dedicated to children with additional needs in the Vale of Glamorgan. You can find out about services provided by the Council such as education, leisure, social services, as well as other voluntary organisations and links to other useful websites. Visit: [www.valeofglamorgan.gov.uk/fis](http://www.valeofglamorgan.gov.uk/fis) and click on 'parents zone', then 'children with additional needs

The Disability Index has its own section and the most recent Index newsletter and referral form can be downloaded by going to [www.valeofglamorgan.gov.uk/disabilityindex](http://www.valeofglamorgan.gov.uk/disabilityindex). The team are also working on developing a directory of local services for children and young people with additional needs. Visit: [www.valeofglamorgan.gov.uk/fis](http://www.valeofglamorgan.gov.uk/fis) and click on 'Parents Zone.'

Hope you all enjoy this edition of the newsletter.

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Rhian Phillips





## Association for the Welfare of Children in Hospital

**The Association for the welfare of Children in Hospital (AWCH) aims to raise awareness of the needs of sick children and their families in Wales. They work with professionals and voluntary organisations, parents, children and young people themselves, to promote quality healthcare for sick children in hospital, community and home.**

AWCH celebrates its 50th Anniversary this year. During that time the care of children in hospital has changed immeasurably. Rather than limited visiting hours, parents are now seen to be essential to a child's well-being, and are welcomed at any time as part of the policy of family-centred care.

AWCH provides an information service, and practical help in the form of a Hospital Travel & Emergency Fund for those families whose lives are bounded by hospital admissions and out-patient appointments, and who are finding it increasingly difficult to meet the continually rising travel costs. The AWCH T&E fund can give immediate help, on referral by a health professional, while waiting for statutory funding to be accessed.

Ideally, AWCH would like to see a statutory hospital travel fund specifically for families of children and young people needing hospital care and treatment, with easy access and less form filling.

Learn more about AWCH, and what we are doing on [www.awchwales.org.uk](http://www.awchwales.org.uk) or email [awchwales.org@tiscali.co.uk](mailto:awchwales.org@tiscali.co.uk)

Caroline Crimp  
Chair AWCH (Wales)

# Summer Disability Teen Scheme

**Hello Again! The Penarth Youth Project will be running the Disability Teen Scheme for 8 days over the Summer Holidays on 30th and 31st July, and the 8th, 9th, 15th, 16th, 22nd and 23rd August 2012.**

The Summer Disability Teen Scheme is an activity based youth provision for young people to access between the ages of 12 and 18 years. Access to the Disability Teen Scheme is by referral only, and on a first come, first served basis. To request a referral pack, please email [info@penarthyouthproject.org.uk](mailto:info@penarthyouthproject.org.uk) or telephone Penarth Youth Project on 02920 405305.

Activities will include arts and crafts workshops, pool, cooking, games consoles and visits to local parks, area of interest, games, music and much more! The times for the Teen Scheme are: 10am until 3pm – Packed lunch and drinks to be provided. The venue is Byrd Crescent Community Centre, Penarth.

For further details about the Summer Disability Teen Scheme 2012 please contact Tracey Downes on 02920 405305

## Rainbow pop in and play

**Rainbow is a pop in and play session for families with pre school children with additional needs who live in Barry is now running from the new times of 1:15-2:45pm every Wednesday.**

During the Summer holidays we will be running at the following times and venues:-

- **Wednesday 25th July**  
Family Fun day at Victoria Park in Cadoxton from 10am-2pm.
- **Wednesday 1st August**  
Under the Sea at Flying Start Family Centre on Gladstone Road from 1:15-2:45pm

- **Wednesday 8th August**  
Sunshine and Showers at Flying Start Family Centre on Gladstone Road from 1:15-2:45pm
- **Wednesday 15th August**  
Fun in the Sun at Barry Island from 10am-2pm
- **Wednesday 22nd August**  
Teddy Bears Picnic at Flying Start Family Centre on Gladstone Road 1:15-2:45pm

Rainbow will resume on Wednesday 5th September at Flying Start Family Centre on Gladstone Road from 1:15-2:45pm.

**For further information contact Ginny Kolmar on 07834 254966**

# Summer Fun



## Summer Play Development

It is that time of year when the summer holidays are fast approaching. The Play & Sport Development Team have organised a range of play opportunities.


The play schemes are for children age 4-11 years and will run from the 13 - 17 August, 20 - 25 August, 28 - 31 August. They will all be held at Palmerston Primary School in Barry and will run from 10am - 3pm each day.

The playschemes are accessible to all children but those with disabilities will need to register. Therefore, if your child would like to attend, please contact Joanne Jones 01446 704809 or Simon Jones 01446 704728.

Play opportunities will include den building, arts and crafts, cooking, outdoor games and sports to name a few.

## Holiday activities for children and young people

The Family Information service has compiled a Summer Brochure 2012, which lists all of the childcare and activities taking place for children and young people in the Vale of Glamorgan in the school summer holidays. The brochure contains information on what's going on in the leisure centres, libraries, parks, sports and play development and all the holiday care schemes. You can see what's going on each week by visiting the FIS web page: [www.valeofglamorgan.gov.uk/fis](http://www.valeofglamorgan.gov.uk/fis) or contact the team by phone on 01446 704704



## Do you know about this amazing Sensory Room?

The sensory room at Western Vale Integrated Children's Centre (WVICC) is for use by families whose children have additional needs. The room is set out with a soft seating/lying area and has light and music stimulation toys and accessories available for use.

This room can be booked for a nominal charge of £1.50 for a maximum of 3 hours. The centre is based on Station Road, Llantwit Major between St Illtyd's Primary School and St Illtyd's Day Nursery.

To book the room please contact either Angharad Evans (Centre Manager) or Paula Malorey-Vibert (Centre Administrator) at the centre on 01446 793030.



# Shine

Cymru

Spina bifida • Hydrocephalus  
Information • Networking • Equality  
Gwybodaeth • Rhwydweithio • Cydraddoldeb

**SHINE Cymru – the organisation that supports babies, children and adults with spina bifida and hydrocephalus living in Wales – offers practical support, information and advice to individuals of all ages directly affected by these two disabilities.**

We are also a source of expert knowledge and guidance for parents, grandparents, brothers and sisters, carers and the professionals who work with them.

For further information on the services we offer, or if you can help with fundraising to maintain our services, please contact: Sian Prince, Regional Support and Development Worker for the Vale of Glamorgan on 029 2051 4978 or email [sian.prince@shinecharity.org.uk](mailto:sian.prince@shinecharity.org.uk)

# Tourettes Action South Wales – Family Support Group

Tourettes Action South Wales Family Support Group is a voluntary group set up by a parent of a child with Tourettes Syndrome (TS). We welcome anyone in the South Wales area, who has concerns or wants to know more about TS and related (co-morbid) conditions. You do not need to have a diagnosis.

We meet on a monthly basis which gives families and individuals a chance to exchange experiences or just meet others with the condition.

We are passionate about raising awareness about this condition to make it more accepted.

We are supported by Tourettes Action who offer a range of services and are working hard to research this condition. They have regular updates on activities, events and conferences throughout the UK. To find out more visit their website [www.tourettes-action.org.uk](http://www.tourettes-action.org.uk)

They also have a helpline 0300 777 8427 which is open from Monday to Friday 9-5.

For more information about the South Wales Family Support Group please email [LisaAngelaHole@aol.com](mailto:LisaAngelaHole@aol.com)

## Carers

Don't forget that the Vale of Glamorgan Council Carers Services also make available a carer's pack with more comprehensive information and signposting for carers. Contact the Carers Development Officer on 01446 704604 to request a copy if you don't already have one.

## Are you a carer?

**Are you caring for a child or young person up to the age of 18 with a disability and or additional needs? If so, are you getting the help and support you need?**

Caring can be rewarding but it can also affect your home life, work life, free time and family relationships. Carers are not paid a wage to provide support and are sometimes referred to as unpaid or informal carers.

The Vale of Glamorgan Council holds a Carers' database so that carers can be kept fully up to date on the services, information and help that are available and relevant to them. The carers' database is confidential and secure and is used to send out Caring Times, the quarterly newsletter for carers in the Vale of Glamorgan.

If you would like to be added to the carers database or if you require more information, please contact James Livingstone, Carers' Development Officer for the Vale of Glamorgan Council on 01446 704604 or email: [CarersService@valeofglamorgan.gov.uk](mailto:CarersService@valeofglamorgan.gov.uk)

## New Regulations and You

**The Welsh Assembly Government (WAG) has recently issued new regulations on how Local Health Boards (LHB) and local authorities work together to support carers in Wales.**

This article gives you an overall flavour of the changes and what they could mean to you. For the full document, follow this link <http://wales.gov.uk/consultations/healthsocialcare/carers/> where you can read the regulations in full detail.

The main thrust of the regulations is consulting carers and keeping them informed. These 2 principles have been the theme of carers' strategies for several years, however there is now a legal obligation to ensure that, among other things:

- Carers are consulted at the right time, that their own situation and needs are taken into account and that they understand the reasons decisions are taken
- Carers' knowledge of the person they care for is respected and used properly
- Carers understand their right to an assessment in their own right
- Carers are told about help and support they may be able to get from voluntary organisations

Carers must also be kept informed. The regulations set out a comprehensive list of information which is appropriate to provide for carers. This includes:

- Medical conditions, medication and treatment of the person being cared for
- Support, such as short breaks, advocacy and transport

- Local and national carers groups, agencies and organisations
- Practical advice about looking after yourself and training to help with the caring role
- Where to get help in a crisis

The regulations also place an obligation on the LHB's and local authorities to develop joint strategies with the LHB taking the lead. In our case this means Cardiff & Vale University Health Board working with both Cardiff and Vale of Glamorgan Councils to ensure that carers are identified and supported in the same way. This should make it easier for carers to access support and also for charities and voluntary organisations to work with all 3 organisations as they carry out their vital work in this area.

No-one would deny that there is still a long way to go in developing services for carers. However, these regulations show there is increasing recognition of just how important the role of carers is along with a strengthening of carers' legal rights.

Carers have told us that they would like earlier and more appropriate information and support to help them in their caring role. It would help us, if you are or have been a carer, if you could find a few minutes to complete the survey which can be found at the link below.

If you would like a paper copy or need help in completing the survey please contact Sue Barrow, Patient Experience Facilitator on 029 2033 5468.

[www.surveymonkey.com/s/PXF5PX7](http://www.surveymonkey.com/s/PXF5PX7)



# Money Information

## Should you be claiming Carer's Allowance?

So long as you are spending at least 35 hours a week looking after someone who receives Disability Living Allowance (DLA) care component at the middle or high rate or Attendance Allowance you may be eligible for Carer's Allowance (CA).

You can make a claim regardless of your relationship to the disabled person – including whether they are your child. The weekly rate is £58.45. However, you can't claim carer's allowance if you earn more than £100 a week after certain deductions (like Income Tax) have been made, or if you are in full time education (21 hours a week). Contact the Citizens Advice Bureau (CAB) Benefit Take-Up Team on 01446 704993 or email: [advice@valecab.org.uk](mailto:advice@valecab.org.uk)

## One-stop shop for benefits advice

Contact a family has a great website called 'Cash Counts,' which is a one-stop shop for benefits advice and money tips for families with disabled children. Visit: [www.cafamily.org.uk/cashcounts](http://www.cafamily.org.uk/cashcounts)

## Disability Benefit for Children Run by the Citizens Advice Bureau (CAB)

Do you care for a child aged up to 18 and want some help to claim or renew their disability benefits?

Has the need for care increased?

Are you getting all of the correct money?

Our Benefit Take-Up Team (Welsh Government funded) can help you. You can either contact us directly on 01446 704993 or visit us in Barry or at one of our outreach services and ask to be referred to the Benefit Take-Up team.

**Email advice:** [advice@valecab.org.uk](mailto:advice@valecab.org.uk)  
[www.valecab.org](http://www.valecab.org)  
[www.advice.org.uk](http://www.advice.org.uk)

CAB offices are available in the following locations at various times:

### Barry

19 Broad Street, Barry

### Llantwit Major

Youth Centre, Station Road, Llantwit Major

### Penarth

West House Cottage, Stanwell Road, Penarth

### St Athan

The Gathering Place, St Athan

### RAF Camp

Gibbonsdown Communities First Office – Aberaeron Close, Barry

# Vale People First

Vale People First has been awarded funds through the Welsh Government's Children and Families Organisational Grant to create a new pilot project, to provide 'peer advocacy support' to parents with learning disabilities in the Vale of Glamorgan.

The key aims of the project are to:

- a) Protect the human rights of people with learning disabilities to be parents and
- b) Give parents with a learning disability the best possible support so that they can provide a safe, stable and loving home for their children, so avoiding the intake of children into the care system.

We will do this by providing regular meetings with the emphasis being on peer mentoring and informal support.

The first meeting is planned for mid June 2012. If you are interested, or know any parents with learning disabilities that may benefit from this service, please contact:

Liz Davidson at Vale People First  
01446 724010



**Local Motion Dance Company, funded by Children in Need meet every Thursday at Barry YMCA Hub between 5-6:30pm. It is a project for young people aged 11-25years with disabilities who have a passion for dance.**

You can catch the members jamming alongside many other dancers on King Square as part of the Big Dance 2012 Street Dance Day on 14th July and they will be performing this summer at Barry Island

Promenade on 22nd July, Cardiff Carnival on 4th August, The Eisteddfod Festival, Llandow on 7th August and the Barry Waterfront Festival in September.

We are looking for children aged 7-10years with disabilities who live in the Vale of Glamorgan, Bridgend or Cardiff who would also like the 'Chance 2 Dance' for a new project starting in September on Thursdays between 4:30-5:15pm at the YMCA Hub.

For further details contact Dance Co-ordinator Emma Mallam on 01446 733622 [emma@vibeexperience.com](mailto:emma@vibeexperience.com) or visit [www.motioncontroldance.co.uk](http://www.motioncontroldance.co.uk)



# Launch of the Disability Index

The Disability Index was re-launched at an exciting event at the Hub, Barry YMCA, on 18 April. Lots of families and young people attended the day, organised by Vale People First and Vale Youth Speak Up, and were able to sign up to the Disability Index.

Young people had a great time taking part in DJ'ing and open mic, graffiti walls, Motion Control Dance and a visit from the V-Pod. While parents and carers and service providers listened to talks from various people involved in providing services for disabled children, including: Dilys Price from the Touch Trust, Tracey Downes, Penarth Youth Project, Helena Jones and Lewis from the Vale Youth Forum and John Cushen from Cardiff & Vale Parents Federation. They were also able to visit the many information stands available.

Vale Youth Speak Up then staged a Jeremy Kyle style show, which was both funny but delivered a real message that young people with disabilities want to lead a normal life and be treated like any other young person.

Mark Davies, Children and Young People's Partnership Manager, opened the event and spoke of the benefits of the Disability Index for families:



“The Disability Index is an ideal way of making sure that children with special and particular needs, and their parents and carers are receiving the information they need.”

“The Index Co-ordinator will also be able to identify and help influence services based on current and future needs of children and confirm whether children are receiving the correct services. It will also allow health, education and social services to coordinate their services in a more joined up way.”

If you are not registered on the Disability Index and would like to be, please contact Becky Keedwell-Jones, Index Coordinator, Tel: 01446 725364 or Rhian Phillips Index Administrator Tel: 01446 704736. Visit [www.valeofglamorgan.gov.uk/disabilityindex](http://www.valeofglamorgan.gov.uk/disabilityindex)



photos supplied by Vale People First



# Support for Families

**Early support is a Welsh Government initiative that provides support to families with children with special and additional needs. They have produced a number of resources that can be used with families to ensure the needs of the child and family are met. The information compiled can be shared with professionals to give them a clear picture of the child's needs.**

I am currently working with families, providing 1:1 support in their homes to assist them in using the developmental journal and family file.

The developmental journal focuses on charting the development of children with special or additional needs. The materials focus on what a child can do rather than what they can't, which helps parents chart their child's progress, record achievements and build a positive record of their child's development.

The family file enables parents with a child with special or additional needs to record information about their child's needs and the professionals that are supporting the family. This can be used to share information with professionals when attending appointments and meetings in different places, as the child's situation and development is being discussed.

These resources are family held documents and are particularly useful for those children who are attending child care or school, as they can be shared with those who care for your child to highlight your child's individual needs and putting them at the centre-not their condition.

If you would like further information or are interested in receiving support with these resources please feel free to contact me – Ginny Kolmar on 01446 731628.

## Pedal Power

**Pedal Power is the working name of The Friends of Pedal Power Project. We are a charity whose Mission is "to make cycling accessible to all". Pedal Power is home to one of the best accessible cycling centres in the UK. We operate out of two centres, one near the city centre and one in Cardiff Bay.**

We have standard and specially adapted tricycles for all abilities and ages. This enables virtually anybody to enjoy cycling.

We offer a full assessment service to members in order to find you the perfect cycle for your needs. Unfortunately, we cannot hire out the adapted cycles without the disabled person being assessed, nor are they normally available to the general public. However, it is possible to hire a side-by-side at the weekend if there is one available.

We know that a good assessment of the cyclist is key to finding solutions that are safe, comfortable and successful. Our trikes have been chosen by our physiotherapist for specific needs, from a

wide selection of manufacturers, who specialise in adapted cycling. Whatever your age or ability we have something that will allow you to pedal or alternatively enjoy the cycling experience with one of our multi-user cycles.

Anybody who has difficulties cycling an ordinary bike requires a formal assessment before they can hire a cycle from Pedal Power. To organise this, please access a membership and assessment form from the website.

Contact us Main Pontcanna Office  
+44(0) 29 2039 0713  
Cardiff Bay Office +44(0) 7775 616411  
Email: [info@cardiffpedalpower.org](mailto:info@cardiffpedalpower.org)  
Website: [www.cardiffpedalpower.org](http://www.cardiffpedalpower.org)