

Here comes the summer...

...school is nearly out, and (hopefully) the sun will shine bright so we can all enjoy the season, have fun and, with the longer days make the most of what's on offer during the holidays.

There are many reasons to celebrate this season, not least as we congratulate our Easter Egg Hunt winners' Toby and Luke - well done and hope you enjoyed your chocolaty prizes!

Taking on board more of your feedback, this, our 14th edition of the newsletter not only brings you information on activities and updates but provides a balance with a selection of articles from the perspective of some of the children / young people and their families. We celebrate the achievements of Bradley and Kacey in our Have your say section on pages 10 & 11, and thank Claire for her open and honest account of her experience of autism in our Spotlight on page 7.

Summer is a time which brings with it the opportunity to do lots of outdoor social activities, which are impossible in the freezing cold winter. Whether you prefer a relaxing day at the beach, or looking for something more active, I'm sure there's something for everyone with lots of options in our Summer Fun section on pages 4 & 5. For some of us, it's also a time to go further afield, discover accessible places to go and how you can keep safe in our Getting out and about section on page 9.

As you're no doubt aware, one of the purposes of the Disability Index is to keep you up to date with developments, information and activities, and with a view to further improving our communication we are looking to launch an e-bulletin to be sent out between newsletters. Interested? See page 12 for details on how you can sign up. And don't forget to check our online Index Noticeboard too.

I hope you enjoy reading this issue, and would welcome your comments and any suggestions you have. After all, the newsletter is for you.

Wishing you the happiest of summer days,

Zoë Duncan Disability Index Administrator 01446 704 736

The Index is funded by the Welsh Government Families First Grant



Congratulations to our Easter Egg **Hunt winners Toby and Luke**





Luke

Come and join Vale Youth Speak up!! Vale People First Getting out, Getting o



Are you a person with a learning disability aged 16 to 25? Would you like to make new friends, increase your confidence and allow yourself to experience opportunities you wouldn't normally get? Then come and join Vale Youth Speak Up!

Vale Youth Speak Up is a group that allows young people with learning disabilities to speak up, take part in fun activities and take charge of the group. We do all sorts of activities, such as making movies that deliver an important message and the movie gets shown around the world.

We also go on foreign trips around the world as well. So far, we have travelled to Poland, Germany, Lithuania and many more!

We also go out on different trips too. We go to nightclubs, live events, or even a trip to London.

We also aim to tackle bullying and

discrimination or any other serious issues that people with learning disabilities face.

The group meet at Parkside Christian Centre. St Brides Way, Barry CF63 1TZ on a Thursday from 17:30 to 19:30. We meet throughout the summer holidays.



For more information, ring Ros Brewer on 07764 968 340 or ring Vale People First on 01446 732 926.

Changing Places, **Changing Lives**

The Changing Places Consortium is a group of organisations working to support the rights of people with profound and multiple learning disabilities to access their community.

They have launched a campaign on behalf of those people who cannot use standard toilets, campaigning for Changing Places toilets to be installed in big public places. There are currently 27 Changing Places toilets in Wales, which are publicly accessible with enough space and the right equipment, including a height adjustable changing bench and a hoist.

To find out more, join the campaign, share your experience, or find a toilet visit: www.changing-places.org

Moving Towards Transition

- You may recall in issue 13 we did a
- Spotlight on Transition, and we informed
- you that we were in the process of developing a Transition Pack.
- The wording has now been approved and
- we've moved on to the design stage. We
- are also considering the production of an
- easy read version of Transition: Moving from Childhood to Adulthood. A Guide for Parents
- / Carers of Young People with Disabilities
- aged 14+

SUMMER FUN

What's on this summer?

Everything you need to know about what's going on in the Vale during the school summer holidays:



Summer Activity Brochure 2015

Activities, play schemes, holiday childcare schemes, events and more for children, young people and families in the Vale of Glamorgan.

Visit: www.valeofglamorgan.gov.uk/fis to view the programme

Telephone the Family Information Service Team: 01446 704 704

Email: fis@valeofglamorgan.gov.uk

Enjoy a day at the seaside

All-terrain beach wheelchairs provided by the Vale-based Intersensory Club are available at Barry Island, giving more visitors the chance to get on to the sand at Whitmore Bay.

There are three chairs, available for loan and free to use, which can be pushed across the sand without sinking, thanks to their wide wheels and unique design.

For more information contact Vale of Glamorgan Tourism on 01446 704 867 or tourism@valeofglamorgan.gov.uk



Grab a bike, and go for a spin around the stadium track



Vale Adaptive Cycling Club operates at Jenner Park Stadium, Barry CF63 1NJ on Wednesday and Fridays between 1pm and 5pm from March until September.

We have numerous specialist bikes, trikes, tandems, enabling children, young people and adults with varying disabilities or limited mobility to access and enjoy the exhilaration of cycling. As we are a not-for-profit club we rely on donations, grants and fundraising to finance the project; and the club is run by volunteers. Suggested donation £2.

For more information please contact Cliff Hayes on 01446 420 533 or valecycleclub@outlook.com

Teen Scheme - Dates for your diary

All Youth Matters (formerly Penarth Youth Project) are pleased to announce the dates for the July and August Teen Schemes 2015. Make sure you mark them in your calendar!

July: Monday 27th and Tuesday 28th August: Monday 3rd and Tuesday 4th Monday 10th and Tuesday 11th

Monday 17th and Tuesday 18th Monday 24th and Tuesday 25th

Disability Teen Scheme is made possible by funding provided from the Welsh Government Families First Programme, and caters for young people aged 12 to 19 years.

Please provide a packed lunch and drinks.

Summer Teen Scheme will be held at Cadoxton Moors Community Centre, Rear Edmund Place, Off Cardiff Road, Barry CF63 2NX

Places are limited and are by referral only and by completion of the Helpful Book.

We are happy to accept a donation of £5 per day for games and / or trips decided by the young people who attend, and recently spent a day fishing with Barry Anglers at the Dow Corning Education Centre. An enjoyable day was had by all Teen Scheme and staff catching fish and releasing them back into the Dock Pond. A huge thank you to Catherine at Dow Corning Educational Centre, and to Barry and

Vale Anglers for all their help, support, teaching and fun!

For further information please contact Tracey Downes on 029 20 211 747 or email cbcp@ penarthyouthproject.org.uk



Teen Schems

Dance the summer away with **Motion Control Dance**

Motion Control Dance provides opportunities to children and young people with disabilities to be able to access, experience and enjoy a variety of dance.

We are delighted to be welcoming London based Candoco Dance Company to run a summer scheme for children and young people with disabilities at the YMCA on the 10th and 11th of August. Participants will be creating phrases that our fantastic tutors will then work into a performance piece on the 13th and 14th August, before the children and young people will perform at Barry Rugby Club on Sunday 16th August.

Cost of the summer scheme will be £20 for 10 hours of dance.

Anyone wishing to participate in the summer scheme or would like to know more about Motion Control Dance please contact Emma Mallam on 07725 038 778 or motioncontroldance@gmail.com

Emma is pleased to announce that Motion Control Dance (MCD) has been successful in obtaining charity status and is now an independent - Charitable Incorporated Organisation (CIO) registered number 1161551.



Look forward to a fun packed summer Play Scheme

- It's that time of year when the summer holidays are fast approaching. The Sports and Play Development Team are organising a fun packed summer filled with activities and games throughout the summer at various locations within the Vale. It's an opportunity for your child to try a range of different things that will build
- confidence and self-esteem, but most of all it's guaranteed to be FUN!

18 to 20 August at Jenner Park

27 to 30 July at Murch Junior

School, Dinas Powys

School, Barry

Please see website for further dates and venues.

For more information contact the Sports and Play Development Team on 01446 704 809.



SPOTLIGHT ON. **AUTISM**





Picture shows members of the Cardiff and Vale NAS Branch at a recent Keynote Speaker Event

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.

Autism is part of the autism spectrum and is sometimes referred to as an autism spectrum disorder, or an ASD.

The three main areas of difficulty which all people with autism share are sometimes known as the 'triad of impairments'. They are:

- difficulty with social communication
- difficulty with social interaction
- difficulty with social imagination

All people with autism can benefit from a timely diagnosis and access to appropriate services and support.

Cardiff and the Vale National Autistic Society (NAS) Branch is a parent led autism support group. The group is run by volunteers, who are mainly parents, who live in the local area. The branch formed in 2004, and offer:

Peer Support throughout the year in the form of coffee mornings, workshops, social evening and fundraising events. At some coffee mornings we have guest speakers who have a breadth of knowledge about disability and support, and others are informal get togethers for a chat. Meetings are held in Cardiff, Barry and Penarth.

Workshops / Keynote speakers, which can include sensory issues; managing stress; anger management; diet; sleep workshops; sibling support; sexuality and puberty; autism research updates; and international speakers. We welcome anyone who has concerns and would like to know more about autism. No diagnosis is necessary.

Family Activities, run by Thrive, have regular soft play sessions for children and young people with autism, and their siblings. The sessions are held at Coconuts every other Sunday from 17:15 until 18:45.

For more information email nascardiff@nas.org.uk or find us on Facebook National Autistic Society - Cardiff and the Vale branch www.cardiffandvaleautism.org.uk

Autism, Our Experience...

Claire opens up to the Index and shares her family's experience, reflecting back on their journey so far.

"We're not your conventional 2.4 family, and when I was pregnant my biggest worry was our children being bullied at school because they had 2 mummies.

My beautiful baby boy was born in February 2011. He had the biggest brown eyes, the chubbiest of legs – our adorable hunka chunk. We had our life planned out, looking forward to seeing our boys grow up together, listening to them laugh and play.

Fast forward 2 years, sat outside the speech therapist's office, eagerly anticipating the appointment we'd been waiting 6 months for. We'd noticed a lack of speech when he was 18 months, his brother was 12 months and had started to try and say a few words. I'm not sure we knew what to expect from that first appointment, he wasn't happy about having to wait and we struggled to keep him occupied. At the end of an hour long appointment the Speech and Language Therapist (SALT) asked if anyone had ever mentioned autism to us...this was the start of our journey.

We had to wait about a year, after being referred to a Social Communication Assessment Pathway (SCAP) for diagnosis, which passed in a blur of speech therapy, paediatrician and ENT appointments. I spent most evenings trawling the Internet reading every article I could find on autism. The more I read, the more I recognised but there was always a seed of doubt...not my boy surely.

Following SCAP completing their assessments we met with the paediatrician for the results. The day of diagnosis had arrived - Autism. We had a name, a label, a diagnosis. A wave of relief washed over me, it was short-lived. A grief-like sadness followed and I found myself crying all the time, worried about what the future held and sad at the change in our flight plan.

Our SALT recommended Thrive Cardiff to us, and we went along to a soft play session, met some lovely "Thrivers" with older children on the spectrum who were further along in their journey.

We spent time talking to one of the mums. The tears started to roll down my cheeks. I felt so sad, but at the same time a little relieved to find such a fantastic support network.

Around this time we attended the Autism Expo in Cardiff, a fantastic day, which was a turning point for us. Up until this point I'd spent every day in tears, worried sick at what the future held. It was a huge stress on our family, and at my lowest point I thought splitting our family in two was the only option. We came away with hope, optimism and a determination to work together to make our family work.

With the help of our SALT we set about teaching our son how to use PECs, and were told to find his motivator. What did he love? That was easy...blowing bubbles. Something clicked and he picked it up really quickly. He has no words, but with the help of little picture cards he can tell us exactly what he wants. His current favourite is frozen tiptops!

We booked on to the EarlyBird programme, which was life changing for us, learning about autism, how to successfully communicate with our son and manage behaviours. I had naively thought before attending that once he could speak everything would be ok, but soon realised strengthening the communication strategies that we had started to put in place was key. Through EarlyBird we've made some very good friends, clicking straight away, and between us we're holding monthly coffee mornings through Cardiff and the Vale NAS branch and helping out with the exclusive soft play sessions organised by Thrive.

We have found fantastic support from other families who completely understand our situation.

Our son is now 4 years old, and having spent almost a year at mainstream nursery it's been decided that he will attend the early intervention base at Ysgol Y Deri from September.

Our year since diagnosis has certainly been a roller coaster of a ride. We're still holding on tight, but we're moving forward with the hope of building on the foundations that we have laid. We have good days and bad days, and don't know what the future holds, but as a family I know we will do our very best for our hunka chunk."

EarlyBird offers hope for parents / carers

If your child is under 5, and has recently been diagnosed with autism, the EarlyBird programme can help you to understand your child's autism, and support you in the period between diagnosis and school placement, helping to establish good practice at an early age so as to pre-empt the development of inappropriate behaviours.

The programme, run by local professionals with experience and understanding of autism spectrum disorders, is a 3 month parent programme, which combines group training sessions for parents with individual home visits, when video feedback is used to help you apply what you learn, whilst working with your child. By using strategies to cope and structured interactions the EarlyBird programme enables you to become empowered and feel back in control, as well as providing you with the opportunity to share ideas and to grow in confidence working alongside the professionals and other families on the programme.

For more information contact Eli Wapner-Carter on 029 2035 2280 or email ecarter@yyd.org.uk



Make Time for a Cuppa

It's your chance to meet and talk to other parents and carers of children and adults with autism, over a cup of tea / coffee in a friendly and welcoming environment. Cardiff and Vale NAS Branch meet at the Pioneer Hall, Beryl Road, Barry CF62 4AN from 10:30 until 12:00 on the following Saturdays this summer: 18 July, 8 August and 12 September. They welcome you to join them.

Useful Links

The National Autistic Society Wales Cymru www.autism.org.uk 029 2062 9312 cymru@nas.org.uk

Autism Puzzles www.autismpuzzles.co.uk 029 2061 6361 autismpuzzles@hotmail.co.uk

The Autism Directory www.theautismdirectory.com in partnership with Living Autism provide a helpline for help and support 0113 815 0210

Thrive http://thrivecardiff.org/info@thrivecardiff.org 029 2033 9895

Vale of Glamorgan Adult Autism Advice 01446 731 105 adultautismadvice@valeofglamorgan.gov.uk

GETTING OUT AND ABOUT

A One-Stop-Shop to Disabled Access Reviews

Euan's Guide, www.euansguide.com, is a website dedicated to disabled access reviews at a range of venues i.e. restaurants, hotels, cinemas, sports grounds etc.

The gentleman behind the site is Euan MacDonald from Edinburgh, who in 2003 was diagnosed with Motor Neurone Disease. Despite this, Euan still wanted to visit restaurants, bars, music festivals, hotels, and so on and initially the only way he could find out if access was suitable was purely through trial and error. After years of investigating, Euan and his family had built up a kind of local directory on disabled access and were keen to share this with others with accessibility needs. This of course led Euan and his sister Kiki to create 'Euan's Guide'.

Since its launch in 2003, disabled access reviews have gone well beyond Edinburgh and the number of venues being reviewed in Wales in starting to grow. Anybody can write a review on the site at no cost, so if you know anywhere that has / hasn't met your accessibility needs, this is the place to let others know.

The venues are each scored out of 5 stars and are marked on their parking facilities, access into venue, their staff and toilet facilities.

The site is summed up through this quote by Euan:

"The aim of Euan's Guide is to empower disabled people by providing information that will





give confidence and choices for getting out and about. Euan's Guide is an alternative to hours of web searching and phone calls and, most importantly removes the 'fear of the unknown' when visiting a venue for the first time."

Please visit www.euansguide.com for more information.

Keep Safe with an ICEcard



Plain and simple, an ICEcard is a card you carry with you everywhere you go. If you are ever in an emergency situation and are unable to speak for yourself, your ICEcard holds all the important information required by first responders to ensure your medical needs are properly and safely met.

It also holds the contact details of the people you've selected to be notified – just as the card says - in case of emergency. Cards are supplied in packs with matching Key Rings and stickers which help to alert first responders that you are carrying an ICEcard.

There is a range of child ICEcards, and in addition there is an optional extra parent card, which is intended for parents of children with special needs, e.g. autism, Asperger, ADHD. It warns emergency responders, in the event of you being unable to advise them, that your child has special needs and should be cared for with this in mind, should you take unwell suddenly or be involved in an accident. The reverse contains standard space for writing emergency contact details and medical information for you, the parent.

Visit www.icecard.co.uk/child-ice



Bradley is Champion of Champions

Mum, Kiki, wanted to share her son Bradley's accomplishment in karate. Bradley is 10 years old and has special educational needs / global development delay due to a stroke before birth. In Kiki's words, he is an amazing little boy who has become Champion of Champions for Vale Karate for the year 2014/15.

I couldn't miss the opportunity to find out more. Here's what Bradley had to say...

"I have been doing karate for 6 years. I love karate as I get to meet with my friends and learning new katas but most of all I like punching and kicking the pads. I had to go to lots of competitions around Wales and win points and medals." A fantastic accomplishment, well done!

Kiki told us that "We wanted Bradley to start a sport to help with his coordination and make some friends. But we knew that group sports like football would not help Brad as he could not follow instructions. When visiting the YMCA I noticed that Vale Karate had special needs classes. We were invited to come and watch to see if he would like it. He did. And the fact that it was a small class tailored to their understanding, it seemed perfect for him.

We were a bit worried at first as Bradley was not very good at listening and we didn't know if he was able to understand the interactions. But after the first lesson with Sensei Rob, we were amazed how much Bradley had learned, and liked it.

Bradley has benefited massively from karate. It's taught him discipline, improved his coordination and focus, increased his ability to listen and concentrate for long periods of time. He has grown through the sport, made some friends for life, and through the competitions has learnt that being different is ok.

We, as parents, have loved seeing him blossom and do something he loves. We have met some fantastic people, and it is something as a family we can all enjoy together."

Vale Karate is karate for everyone, and is run by Chief Instructor Rob Copeland 6th Dan and secretary, Cathy Copeland. They are based at The Hub on Court Road, Barry and hold special needs classes on Tuesday from 18:00 until 19:00, and on Saturdays from 13:00 until 14:00. To find out more visit: www.valekarate.com or telephone Sensei Rob on 07904 582 123.

SAY...

Kacey is Prestigious Penarth Young Citizen of the Year 2015

For those of our readers who attend the Teen Schemes, you will no doubt recognise Kacey, who was nominated by All Youth Matters for all her hard work, effort, commitment and dedication she has brought to the projects she has volunteered for. Kacey was nominated in the Community category and was placed joint winner.

Her tireless volunteering didn't go unrecognised as she was also awarded Joint Winner of the Prestigious Penarth Youth Citizen of the Year 2015!

In her own words, Kacey tells the Index about her experience:

"I was originally involved with the Information Shop in Penarth from a young age so when that closed down I moved into a youth club where there were always plenty of opportunities to get involved. I liked having responsibilities and taking part in decision making. One of the projects I volunteered for inspected All Youth Matters' Disability Teen Scheme on the Children and Young People's Standards for Wales and when I saw the amount of fun that the young people were having because of the staff members' engagement with them, it made me want to be in their place so that I could make a difference too.

"The best thing about volunteering has to be noticing the differences that you're making. Seeing that you're making someone smile or helping someone to achieve something they wouldn't dream of being able to do, is a really good feeling. Seeing them being proud of themselves because they've achieved



something amazing, is so rewarding.

"It has definitely changed the way I look at people and their lives. I'm much less judgmental and I get to know someone and their background first. It's also opened up many opportunities and has given me an idea of what type of things I'm good at and what I would like to do in the future.

"It is nice to be recognised for the thing's you're doing. Obviously you know you're making a difference when you can see change but to feel appreciated by the community is even nicer. I think giving these awards is quite important too as it raises awareness of the good things young people are doing within the community.

"Volunteering can definitely help you grow as an individual. You're allowed to take on responsibilities which help you to gain independence and life skills. It can open loads of opportunities and career prospects for you. I've also made some really cool friends and also know that if I ever needed anything, I'd have people to turn to for advice."

Find out more about All Youth Matters (formerly Penarth Youth Project) and their summer Teen Scheme on page 5.



Cardiff and the Vale Parents' Federation have moved!

From 15th June 2015, we will be situated at: Sbectrwm, Bwlch Road, Fairwater, Cardiff CF5 3EF. Our new phone is 029 2056 5917.

Please email admin@parentsfed.org for any enquiries.

The Parents' Federation is a parent led charity run by and for families and carers of people with a learning disability.

We offer information and signposting services, speak up for carers and coordinate a variety of face to face support services. Please contact us for more details or pop into the new office for a chat!

All Youth Matters relocated

Building works are currently being carried out at Byrd Crescent, home to All Youth Matters (formerly Penarth Youth Project), and they have temporarily relocated to Aberaeron Close, Gibbonsdown, Barry, Vale of Glamorgan CF62 9BT Telephone 01446 677 337

Have you signed up to the Index E-Bulletin?

Many of you have expressed an interest in receiving regular information during the times between the Index newsletters being published.

We made a start by introducing the Index Noticeboard and are now looking to develop that further by producing a regular e-bulletin keeping you updated throughout the year. To sign up to receive the e-bulletin, all you need to do is provide your email address if you've not already done so. Either call on 01446 709 736 or email disabilityindex@valeofglamorgan.gov.uk If you don't have access to email and would like to be included please just give me, Zoë, a call.

Down's Heart Group has a new telephone number!

Please note that with immediate effect we have a new telephone number. You can now call us on 0300 102 1644 or fax us on 0300 102 1645.



Calls to 03 numbers are charged at the same rate as making a national call to a 01 or 02 number and are included in many providers' inclusive packages.

Disclaimer

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