

# Speak Up

PARENTS  
VOICE  
ISLE OF  
WIGHT

E-NEWS

ISSUE 1



## Parents Voice - Isle of Wight - Your Children - Our Voices

### Parents Voice Isle of Wight, your voice within the community for children with SEN

The Parents Voice Isle of Wight group has been established for a relatively short space of time as some groups go, however in that short space of time the group has grown its number and its skill base.

Earlier in the year we participated in the SEN (Special Educational Needs) day at the Isle of Wight College. Parents Voice had a stand in the main hall and met parents and professionals alike, we were quiet taken aback at the

amount of people gathered in one place, all looking for support and help in some way.

Next on our agenda for the year was our Speech and Language Therapy (SALT) event held at Rookley Country Park, again a really good attendance, from both parents and professionals.

So why am i telling you all this? well from my point of view as the writer of this **Speak Up**, I wanted to portray to you the things that us as parents, let alone as Parents Voice have been involved in. In fact this is why this newsletter was created, it's our voice, and we feel at Parents

Voice that all our voices are very important in the world of SEN. So we aim to bring you a bit of jargon busting, some news, events, maybe even interviews from people like parents, kids, carers and officials.

### Whats in it?

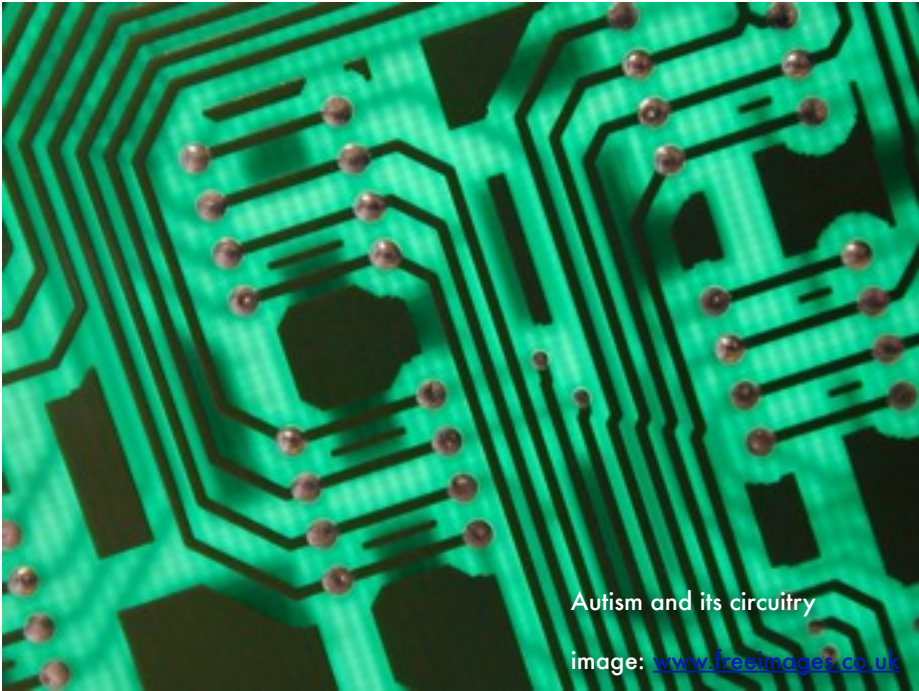
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### Autism quote

"I love how Autism has given me the appreciation of both my sons achievements, no matter how small or large, every achievement is celebrated"



# 2011



Autism and its circuitry

image: [www.freeimages.co.uk](http://www.freeimages.co.uk)

## Living with ADHD/ASD a Dads point of view

As it's the first one, and it will probably be my only chance, I thought I would steal the lime light, my eldest son was born in 2003 and as far as we were concerned, the most beautiful, perfect thing that the world had ever seen, we were lucky, and despite a very difficult delivery he was here, he was born at last!

As with all conditions like ADHD they take a time to manifest, he wasn't born with a large sticker saying ADHD sufferer, nor did he come with a set of instructions.

My wife first raised her concerns to me following a mother and toddler group. Prior to going to this we had noticed he was methodical in his ways, he liked structure, he loved lining up his toy cars and could seemingly memorise books that were read to him, even quoting you the correct word if you read it wrong. So when she went to a toddler group his lack of, shall we say, participation was noticeable compared to the other children, he wasn't bothered by other children, yet held his hands over his ears if they chose to make a loud noise.

So home my wife came, and we talked, my reaction was one of, don't be daft, and he's just the same as all the others. Yet I firmly believe in all these things that parents know their children, and they know them the best. These concerns continued, and coupled with his growing agility and strength became more and more apparent and noticeable. A trip to the GP who said the words "Have you ever considered ADHD"

AAAAAAAAAAGGGGGGHHHHHHHHH!!!!!! was my reaction, he's ill!, he's different! he cant get on in life!!!!

And.....breath

It took some time to get the diagnosis of ADHD (and later co-morbid ASD), many

tests and visits to and from professionals, all poking our boy about. It upset me greatly to see him being different to other children, to see him react so differently to his peers, I wondered how he would ever get on in life, and most importantly to me, I felt I had failed him terribly.

My frustrations have matched his for some time now, and the circuitry of Autism and its hereditary links are not for me to comment upon, I now try much harder to accept his ways, his habits and ticks, and his need for information and structure, but I still find it hard.

But then I see what he can achieve, I see that with our support he will do as well as he can, he is the most loving, considerate little boy that I know and through all my frustrations, all my being hard on him for acting differently sometimes, his want has always remained the same - for me to love him.

Parents Voice Member

## Autism Myths:

Children with autism never make eye contact

Some do make eye contact, and some make eye contact after working for years to learn to make eye contact.

Inside a child with autism is a genius  
Children with autism have a wide range of IQ scores and skills. However, a child that may remember the birthday of every child in their class may not remember their names.

Children with autism can't show affection

This is difficult for most children with autism, but not always true. Bonds and affection can be achieved in many cases but it takes work, time, and patience

Progress means a child does not have autism

False. Progress means hard work, love, and support is paying off.

Affection and smiling at you means a child does not have autism

False. All children are different and with time, work, and love many that don't show affection will learn to show affection.

Bad parenting causes autism

False

Info taken from [www.pains.org.uk](http://www.pains.org.uk)

## Meltdown prevention Plan

Create an anxiety plan when someone with autism is feeling positive about things. An anxiety plan is a list of things and situations that cause anxiety as well as solutions and strategies they can use to help them manage their anxiety levels. The plan can be adapted, depending upon how well someone understands anxiety- Autism.org



## HELP:

### Listing of organisations

#### Isle of Wight Council

The Isle of Wight Council's website has a huge list of useful links on a wide variety of subjects

#### Hemihelp

HemiHelp is a membership organisation offering information and support to children and their families affected by hemiplegia. Hemiplegia is a neurological condition that weakens one side of the body, and affects one child in a thousand. It is sometimes described as a form of cerebral palsy, and the effects are similar to those of a stroke. 0845 1232372

#### Cerebra

Cerebra is a unique charity set up to help improve the lives of children with brain related conditions through researching, educating and directly supporting children and their carers. 0800 3281159

#### Contact A Family

Contact a Family provides support to parents / carers of children with disabilities and also helps parents contact other families who have similar conditions. 0808083555

#### Parent Partnerships

Parent Partnerships helps parents and carers whose children have special educational needs, from pre-school age until they leave school. We support parents across the Isle of Wight. If you or your child's teacher think there may be a special educational need, we may be able to help. 01983 825548

### IOW Inclusive Football Football Festival

10am to 3pm at Medina Leisure Centre, Fairlee Road Newport. Pop along or enter your team. Contact esseffsean76@hotmail.co.uk



### Web - A Boy With Aspergers

On one of regular tip toes through the internet, always on the hunt for valuable information to share with you, I came across A Boy with Aspergers written by a lady called Claire, a mother of three children, one of which has Asperges Syndrome. The website contains product reviews and information on Aspergers, along with Claires own views on the day to day of living and dealing with Aspergers. The blog is really a good read, and quiet a wealth of information, find it [HERE](#)



### Lego Club

If you have not heard of Lego club its time you did, Lego club has been set up to benefit children with Autism or Asperges that enjoy playing with Lego.

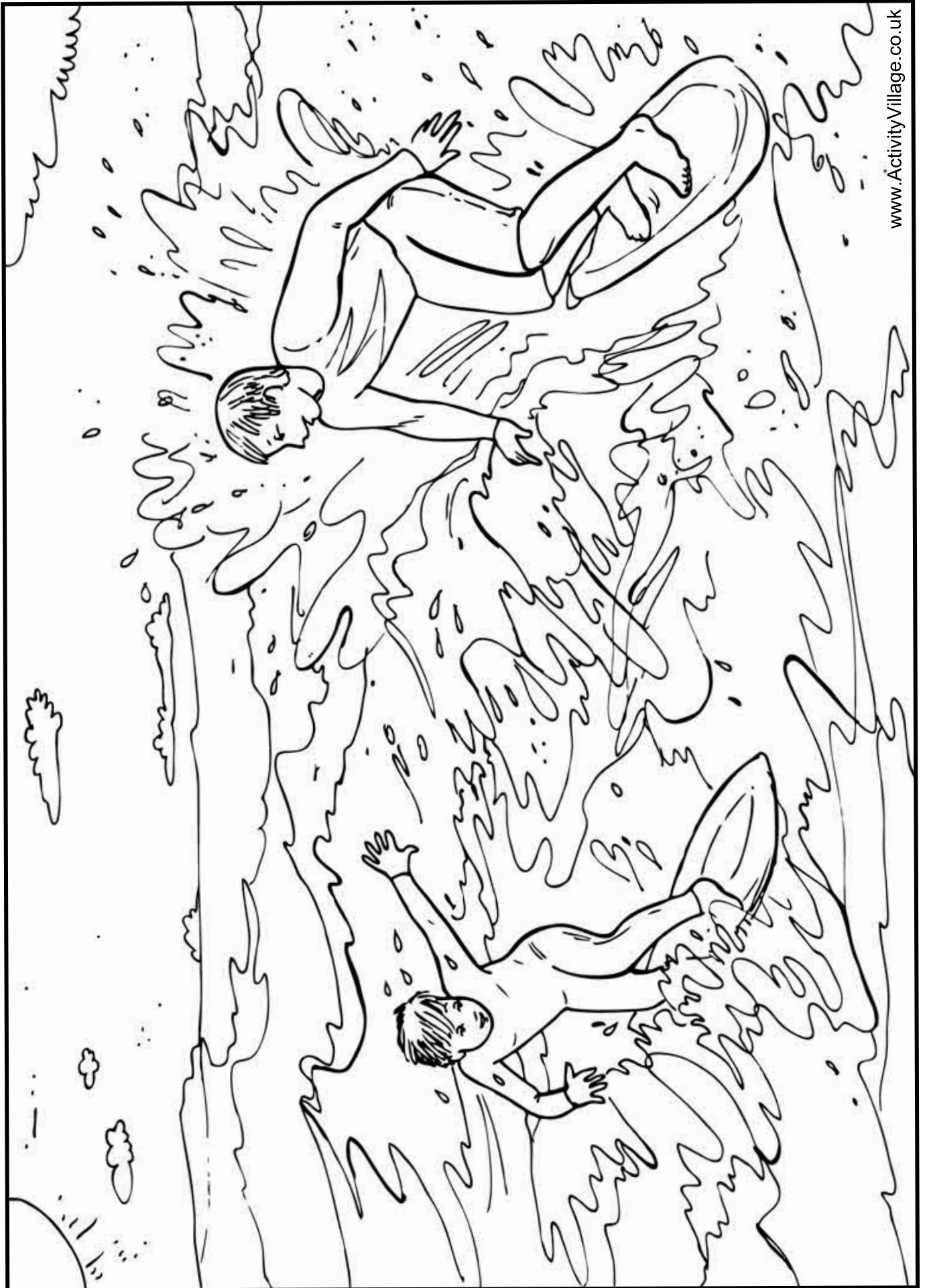
The 3 aims of the Lego Club are

- Improve social interaction, communication & confidence for ASD children
- Provide short respite for parents/carers
- Enable siblings of ASD children to interact

They ask for a contribution of £2 per child per week to cover the costs of equipment & refreshments. You can book your child onto as many or few of the sessions as you wish.

Sounds good and it is good, so give them a call.

To book a place or for more information, please contact: Gillian Elsom, Lego Club Leader email: [elsomacres@hotmail.com](mailto:elsomacres@hotmail.com), Mobile: 07771 920411



## Parents Voice are

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Gaynor Boxall

Vicky Gouldborn

## Poem

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland." "Holland?!" you say. "What do you mean, Holland?" I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.

But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to some horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy a new guidebook. And you must learn a whole new language. And you will

meet a whole new group of people you would never have met. It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts. But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes, that's where I was supposed to go. That's what I had planned." The pain of that will never, ever, go away, because the loss of that dream is a very significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

Written by Emily Perl Kingsley

## Have your say:

### Email us

Want us to feature you in the ENews? then please get in touch. Doing an event? tell us about it

### Kids



Kids get in contact, if you have a joke you want to tell us or a picture you have done then send it in. If you have done something good at school, tell us about it, in fact, whatever you have done that you want to share, send it to us and we will feature it if we can, lets show everyone what you're up to.

### PARENTS VOICE

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