



Positive Parenting for Children with Autism Spectrum Conditions



## Letter from the Editors





Specialised services exclusively designed to meet the needs of young people with autistic spectrum conditions and their families.

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For more information contact Amy Stanion, Services Coordinator Tel: 0161 443 4060 Email: amystanion@cygnethealth.co.uk



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Each book contains 12-16 pages, A5.

- James has Sensory Processing Disorder Jack has Asperger's syndrome
- Daniel has Dyspraxia Katie has Autism



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### Hello and a **Happy New Year**

from all at

SINCE we have plenty of new readers, we feel it's worth recapping on our story so far. Co-editor Debby Elley is a parent of twins with autism and a iournalist: Friend and co-editor Tori Houghton is a speech and language therapist specialising in autism. We met in 2006 and there's not been a dull moment since! The following year we met our current graphic designer Jo Perry. With photographer Jennie Fielden and volunteer distributor Tim Tuff, our team was complete.

Tori and Debby came up with a pilot issue of AuKids for our local area of Stockport in 2008 after bemoaning the lack of good material available for parents. The idea took off - and through the generosity of sponsorship and grants, we're still here and now cover the rest of the UK. All this just from three people working at their home computers! Nothing fancy, just us!

In these hard economic times it's quite something to be running a charitable magazine and we could not have come this far without some very generous help from our sponsors and our readers. Many thanks to all of you for helping AuKids to grow. We hope with your help to reach more parents than ever this year.

## Have a great 2011!

## Tori and Debby

Congratulations to the winners of our Issue 9 competition to win a Dear John DVD.

They were: Linda Dickinson of Middlesborough; Lorraine Cason of Norfolk; Cheryl Travis of Oldham, Lancashire and Michelle Cullen of Cheshire.



Tim Tuff has autism and is AuKids' distributor. His work over the last year has helped us to reach a larger audience and his constant promotional ideas keep us on our toes! Here's a quick word from Tim:

'AuKids magazine has helped me to meet lots of different people and it has helped me to understand my problems better and other's problems and coping strategies. It is nice to have a magazine to help parents and children with autism spectrum conditions.

I enjoy helping people - I've also found that some of the articles help me understand myself better. It's also nice to have the responsibility of distributing the magazine. I enjoy looking for stories and articles for them - I cut them out and wait until Debby delivers the magazines to me, then I give her a bag full of cuttings and useful information that I've found on autism.

I have a part-time job in a High Street store where I work in the warehouse and I have a support worker who helps me there. The people I work with don't always understand autism. They don't always understand that I get stressed when things change. I smile and laugh a lot to myself, too, even when I'm upset it gets me into trouble when people think I'm not being very

Debby and Tori have become good friends. Because they understand autism I've gained lots of confidence and I know that they trust me and appreciate all that I do. I tell everyone about the magazine and I leave copies everywhere to get more readers!'

Our front cover star is Elliot Brady - see spotlight Page 12.

PHOTOGRAPHY: PRINTING: GRAPHIC DESIGN: Tori Houghton and Debby Elley Jennie Fielden BA (Hons) Minuteman Press Stockport



www.periscopestudios.co.uk

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#### WHAT'S IN A NAME?

Orchids are beautiful plants which, much like kids with autism, require very specific conditions to grow. If they get them, they thrive. That's why we called this magazine AuKids. AU is also the chemical symbol for gold.

Want to read our next issue? Not a subscriber? Subscribe NOW at www.aukids.co.uk or send a £10 cheque with your name and address on the back, payable to AuKids magazine to: AuKids, PO Box 259 Cheadle Cheshire SK8 9BE.

## Newsbites

Fitness Fan Takes On Twice the Challenge

for Autism Day

A Manchester fitness enthusiast will be marking World Autism Awareness Day on April 2nd by embarking on a gruelling double challenge to raise funds for the National Autistic Society.

Brendan Rendall, 32, who works for Time Babysitting Ltd, a North West agency specialising in autism, will be taking on a 981-mile cycle from John O' Groats to Land's End before instantly following it up with the London Marathon on

NAS and an orphans' charity Friends of Mulanje Orphans (FOMO) in Malawi.

"As well as the challenge of pushing myself

April 17th. Cash raised will be divided between the

"As well as the challenge of pushing myself physically, I wanted to do something to raise the profile of autism," explains Brendan.

"Before working with young people with autism, I didn't know anything about the condition. Now it's such a big part of my life, I want to get other people thinking about it. My challenge has already sparked off some media interest, which is getting people talking."

You can support Brendan by holding a fundraiser or sponsoring him at uk.virginmoneygiving.com/brendanrendall and following him at www.twitter.com/brenbochallenge.

Brendan aims to raise £6,000 for each of his charities.



### Infant Scientists Wanted!

Are you pregnant, or do you have a baby between the ages of 0-9 months who has an older brother or sister with autism?

The British Autism Study of Infant Siblings (BASIS) is a UK wide network of researchers. Our aim is to learn more about the early development of baby brothers and sisters of children with autism. We hope our studies will in the long term help to improve early detection and diagnosis of children with autism.



We are currently undertaking a project working with parents to maximise opportunities for social communication with their baby in infancy. We are very keen to work with families in the North West region.

This project will take place mostly at your home but families must be willing to travel to the Babylab in central London for some visits. Participation is voluntary and we always take your child's needs into consideration during the visit. We will reimburse all your travel costs and special arrangements, e.g. hotel accommodation, will be available for the London visit.

If you are pregnant, or have a baby between the ages of 0-9 months who has a full sibling diagnosed with an autism spectrum disorder, please contact us for more details.

BASIS, The Babylab, Centre for Brain and Cognitive Development. Tel: 020 7079 0761 E-mail: basis@bbk.ac.uk or visit www.basisnetwork.org

## Parents Launch New School for Autism

A NEW special school in Oldham run by parents of children with autism is taking its first pupils.

Located in Grasscroft, Oldham, Bright Futures School specialises in provision for children with autism using a new approach which is heavily influenced by the thinking and research behind Relationship Development Intervention (RDI)<sup>®</sup>. www.rdiconnect.com



The school focuses on addressing the core difficulties that lie at the heart of autism including rigid thinking, managing uncertainty and change, social interaction and

understanding and managing emotions.

After struggling to find any appropriate provision for her son Philip, who is diagnosed with Asperger's Syndrome, parent Zoe Thompson embarked on the RDI programme at home.

She says: "RDI seeks to give children with autism another chance to master the developmental steps they missed the first time round so that they can cope with - and enjoy - the unpredictability and uncertainty of life."

The school caters for up to ten pupils with statements of special educational needs who have a diagnosis of autism and are between the ages of five and 14.

For further information look up www.brightfuturesschool.co.uk or contact info@brightfuturesautism.com

### **Language Researcher Needs Volunteers**

Many children with autism have difficulties acquiring language, and research is being done to investigate the causes.

Camilla East is a 4<sup>th</sup> year speech and language therapist looking for children with autism in either the **Manchester** or **Reading** areas between **five and** eight years old who can speak to participate in a research project aiming to improve the ability to process language. This will take approximately 60 minutes during which the children will engage in some computerised sentence repetition tasks.

For more information contact Camilla at camillaeast@hotmail.com or 07514 494 889

### Coming up in 2011

### **Public Information Day**



Cheshire Aspergers Parents Support, known as ChAPS, is holding its first **Public Information Day** at The Daresbury Park Hotel in Warrington.

The conference, which runs from 9am-4pm, features our very own expert panellist **Luke Beardon**, Educational Psychologist and Senior Lecturer in Autism at Sheffield Hallam University. He'll be discussing the propensity of secondary psychiatric disorders in autism and talking about the future needs of adults with the condition.

A choice of afternoon presentations and workshops (which you need to reserve in advance) will feature four speakers - Chris Barson of Positive About Autism; Dr Andrew Curran, paediatric neurologist specialising in autism at Alder Hey Children's Hospital; Consultant Psychologist Dr Barry Holland and Professor Digby Tantam. Topics include developing positive approaches to difficult behaviours, bullying and diagnosis.

Attendance fees are £30 for parents, £15 for ChAPS members and £70 for professionals. Refreshments include a two-course hot lunch. For a conference application form, e-mail Jo Garner at info@asparents.org.uk or call 01928 722384.

To find out more look up www.asparents.org.uk

### **Communication Conference**



Edge Hill University in Ormskirk, Lancashire, is holding its **Addressing Autism/Asperger's Syndrome** one-day conference with

Communication as its theme. The fee is £180 for professionals and £75 for parents but there is an early bird discount of £20 for those who book before the end of March.

For more information call 01695 650738 or look up www.edgehill.ac.uk/events/2011/05/20/ conference-addressing-autism-asperger-s-syndrome

### **Emotional Well Being**



The Scottish Society for Autism's Annual National Conference, with its theme Autism: Risk Factors to Emotional Well

Being is taking place at the Hilton Glasgow Grosvenor Hotel. Look up www.autism-in-scotland.org.uk or contact CETA (The Centre for Education and Training in Autism) on 01259 222032.

Do you have a conference that you'd like to publicise in AuKids? Write to us at aukidsmag@gmail.com

## Ask the Experts

"My family are hostage to my son's rigid routines.

Do we adapt our lives around him or are there techniques we can use to influence his rigid behaviour without causing a meltdown?"





Tori Houghton

Specialist speech and language therapist in autism.

Helping children to deal with their rigidity will not only make family life a lot easier in the short-term, but it will also help to prepare them for the constant changes that they will face in adult life.

It's understandable to be fearful of the strength of a child's emotions when they are being rigid, and to want to avoid reprisals in the form of meltdowns.

Any child, however, needs boundaries and if parents struggle to intervene then the problem will only get worse. The key is to tread the fine line between respecting your child's strength of feeling and creating boundaries that will enable you to function as a family.

Try to gain more information about the reasoning behind the behaviour, not only focusing on what your child is saying, which may be misleading, but also on the non-verbal signals which may be more telling.

Often it's fear of change that creates rigidity, because sameness is security. Preparation is important in some situations - a child who

has change imposed on them will respond more rigidly, for instance, than one who has been prepared for a situation with visual support and/or timers. Introducing change gradually is another good method of preparation.

Distraction can work if the fear of change is not overwhelming. Listen to the anxiety and demonstrate that you've heard and respected it. If you promise to talk about something later, make sure you do make time to discuss it and you build up trust.

Dealing with uncertainties can be a cause of rigidity - people with autism, in an uncertain world, like to feel certain. Make sure your child understands that uncertainty is okay and that they reserve the right to change their mind if they try something new, whether it's new food, a different activity or going to a new place.

A querying tone of voice from an adult can also lead to uncertainty in a child. Be straight - don't imprison them with no choice at all, but don't give them too many choices either - make your request nice and simple.

Lastly, give your child a degree of control with smaller choices, even if you're in charge of the bigger picture. They may not be able to choose whether or not they go to stay at grandma's, but they can certainly choose the toys and books they take with them.

In giving your child some control, you'll establish more trust when it comes to the larger decisions that you have to make for them.



Peter Lawson

Services manager at the Stockport branch of Cygnet Springside, a facility which provides specialist autism residential and outreach services.

Call: 0161 443 4060 Email: peterlawson@cygnethealth.co.uk

Changes of routine are inevitable. They are a part of life and necessary in order to maintain positive lifestyles. Changes in your son's routines should not be avoided; rather, they can be opportunities for him to learn to cope with change more effectively.

Your son may not comprehend some of the cues associated with changes and therefore not be prepared for when they occur. Develop a visual schedule for him (or use an existing schedule) which identifies his usual routines, in a format (such as symbols) appropriate to his level of understanding. Where changes occur, work with him in making amendments to his schedule, using a 'change' symbol relating to the new activity.

When a change is imminent, describe it in detail relevant to his understanding. Include things like where/when the change will occur, who will be involved, how long it will take place for and the anticipated outcome.

A Social Story<sup>™\*</sup> is particularly useful in providing a 'preview' of changes. It can be used to describe positives within the change, emphasising things that your son likes to do and that are familiar to him. You could use photos/pictures with the story to further engage him and to provide visual reference.

Prepare your story. Avoid ambiguity, account for literal interpretation, and your son's level of comprehension. Include things that will remain familiar to him during the change in routine and things that might be different than usual. Also include self-help coping phrases for him to use, such as 'it's different today' and 'it's a new thing today'. Repeat the story several times prior to the routine change.

Give warnings of pending change, for example, 'in five minutes, we will be going to'. Similarly, warn of the activity/event finishing. Some children respond to start and finish cues such as 'traffic light' cards, with green indicating the start of a new activity, amber for nearly finished and red for finished.

\*See Issue 9 for more on Social Stories.





Luke Beardon

Luke is a senior lecturer in autism at The Autism Centre, Sheffield Hallam University

Rigidity and routine are often associated with autism. For me, the critical issue is understanding why there is such a need for them. I believe that all individuals need to feel stable in their day to day living, and that people with autism lack many of the things that neurotypical people (subconsciously) have that lend high degrees of stability.

The neurotypical population can communicate effectively with one another, understand each others' behaviour, can predict events, socialise easily, intuitively know what to do in almost any given situation, how to do it - and when to stop doing it. The list could go on!

Most people with autism are not in such a position; indeed, pretty much all of that is an extreme challenge to people with autism. As a result, the autistic population does not have the luxury of such areas of stability and so have to develop them themselves.

Frequently, individuals will develop routines that they can rely on for their stability - and/or rely on things that appear to remain the same every day (for instance, a route to school, or the layout of a room). As a result, when routines or other areas of stability are changed, the individual can become extremely and understandably - distressed.

In order to balance out the overall family's needs and the need for routine, I think that developing higher levels of global stability for the individual with autism is critical. Better communication systems, predictability of events, reduction in sensory overload, development of an understanding of NT behaviour all of these will increase global stability and reduce the intense need for rigid routines and 'sameness'. The higher the levels of global stability, the less need the individual will have for their specific routines.

## Together for autism

Together we work across the spectrum and from birth to adulthood. The Together Trust operates residential homes, short break services (residential and fostering), supported living, Inscape House Schools, a specialist FE college and community support.

We can deliver specialist assessment, consultancy, diagnostic and speech therapy services, as well as training for parents and professionals.



To find out more email enquiries@togethertrust.org.uk phone 0161 283 4848 or visit www.togethertrust.org.uk

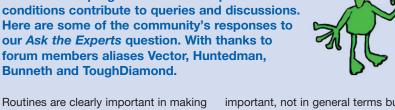


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## WrongPlanet.net

Wrongplanet.net is a web community where adults with Asperger's and autism spectrum conditions contribute to queries and discussions. Here are some of the community's responses to our Ask the Experts question. With thanks to forum members aliases Vector, Huntedman, **Bunneth and ToughDiamond.** 



someone with autism feel safe and inflexibility stems from feeling out of control in an environment or situation. Stress is an important factor. The less stressed, the more flexible people are able to be.

One of our contributors, Vector, used to carry a book around with him as a means of escaping disruption to routines and he now uses an iPod for the same reason. He suggests helping your child to develop healthy, socially acceptable ways to find comfort when things change.

Another contributor, Huntedman, highlights the importance of explaining to your child why the change is

important, not in general terms but outlining the advantage it gives to the child themselves.

Bunneth, meanwhile, advises choosing battles wisely and suggests starting with one very small change with plenty of warning. "Don't force someone to become more flexible by changing things which make them unhappy," he advises.

ToughDiamond sums up by saying: "I always feel that I need to be treated the same way as a good gardener would treat a plant - making changes gradually. If you're going to re-pot a plant, you would try to do that without disturbing the soil that's already around the roots.

"If you want to remove a plant from a warm room to the harsh outdoors, you do it in stages. It may be helpful to enshrine some routines (i.e. respect them and promise not to mess them up) so that he can feel that there are some things he can trust will remain stable.

"Sometimes it's more the fear of losing everything that makes a change scary, even though the change itself affects far less than everything."

"If you're going to re-pot a plant, you would try to do that without disturbing the soil that's already around the roots."



## Ready to Launch?

### It's a New Mission for the Numberjacks

WHETHER or not your child is nutty about the Numberjacks - and many autistic children LOVE them - the show's latest spin-off will be welcome news. A new online maths site, titled Numberjacks: Mission to Learn, seeks to build on the show's educational focus. DEBBY ELLEY spoke to Numberjacks' creator and writer Chris Ellis to find out more.

Launched in 2006 after the BBC commissioned Open Mind Productions Ltd to create a show with maths education as its focus, the Numberjacks have quickly become one of CBeebies' biggest success stories. The

BAFTA award-winning show

consistently rates inside the top ten of the channel's most popular programmes and sells to more than 60 countries with huge popularity in Italy, Australia, India and South America, (where it's known as Os Supernumeros!).

Numberjacks writer Chris Ellis tells AuKids: "I've always believed that children learn best through stories. We wanted stories to be central to Numberjacks".



### Q: How do I become an agent?

A: You can be a good agent by learning and practising the agent skills - looking, listening and thinking, solving problems and thinking about numbers and shapes. If you want to practise with the Numberjacks, you can also sign up to Mission to Learn.

#### Q: Whose sofa do the Numberjacks live in?

A: Even I don't know where that is. It could be any sofa - it could be your sofa. So always keep an eye out.

#### Q: Who is your favourite Meanie?

A: I am most appalled by Spooky Spoon, partly because she reminds me of Mrs Thatcher. I quite like The Puzzler because he's not really a Meanie if you listen closely he actually quite likes the Numberjacks beating him. He is an ex-DJ and it's really payback for the time he wasted turning people's head to mush with bad music, so he goes out there to challenge the Numberjacks.

#### Q: Why is the Numbertaker so scary? A: Well, he has to be a bit scary to make the stories exciting. If he wasn't scary, it wouldn't be so 'tingly' as one viewer

called it.

The tales also feature child heroes of both sexes, giving its audience (mainly three to six year-olds) a strong identification with the Numberjacks. "We did it soon after The Tweenies, where there was always the grandad to sort things out. We didn't want to do that and nor did the BBC. The only adults you see in Numberjacks are ones with problems - the children have ownership and responsibility," explains Chris.



ON A MISSION: (Above and top right) Stills from the new Numberjacks Mission to Learn online game.

A surprise success has been the show's popularity with autistic children. Says Chris: "We started getting e-mails from parents, I had one who said 'I hope you know you've created an autistic child's dream!' We had another really touching e-mail because it gives kids a little bit of the from a mum who told thrill of playing out on their own," says us it was the first time Chris. "I was brought up in the Fifties and as she'd been able to a four year-old I experienced playing out, with communicate with older friends looking after me. Kids her child. It was today have very little experience lovely, and I don't in the best sense - of creative think people realise danger. The show seems to how little feedback give some kids a sense of the programme real exhilaration and

He was particularly Aiming High: Chris as delighted to strike a chord a little lad, all together with an autistic audience now...awwww. because Chris's own son, David, who is 16, has autism. Chris's wife coruns the National Autistic Society's local support group in Dorking, Surrey, and the family have recently fought a lengthy tribunal to move David into the further education school of their choice, working with support from the charity ASSET\*.

excitement."

So why is Numberjacks so popular with autistic children? The maths focus is the obvious reason, but Chris feels that other factors, such as its characters' predictable and simple faces, plus the programme's set pattern of events, are also strong attractions.

The good news is that the programme makers have now launched a website to help children to develop their maths.

Numberiacks: Mission to Learn is a subscriptionbased site that allows children to explore the Numberjacks' world as an agent, undertaking their own missions and improving their knowledge as they go. Happily, the game's programmer, Pete Crawford, is a rare character, with a background

\*www.asset-ab.ora

makers get."

## Computer



in teaching and as a maths consultant. Bringing his own expertise to the game, he was able to work with the show's small team of producers to refine the original idea into a complex finished product that is visually impressive and allows players the opportunity both to explore and improve every time they log on.

Following the maths topics set out in the UK Early Years Foundation Stage and the Primary Curriculum, the game develops children's problem solving, counting, number recognition and calculating skills, as well as enhancing their knowledge of shapes, measuring, position, patterns, and data handling.

The purpose isn't purely to educate children though, but to show parents that with a bit of creativity, maths can be introduced into daily life and can be fun.

Chris explains: "Often parents have not had a very good experience at school and they're a bit uncertain about doing maths with their kids. Mission to "It's partly true that Learn is good modern maths, one of the reasons the which may not be obvious Numberjacks are successful is

to parents." His hope, says Chris, is that parents will use the knowledge away from the computer to make maths fun during mealtimes, or when out in the car or shopping.

> "Even focusing on maths in the supermarket can help kids with autism, who can have difficulty in those situations," he

To try out Mission to Learn free, go to www.njmtl.co.uk

### **DISCOUNT FOR AUKIDS READERS**

The Numberjacks team has generously offered AuKids readers a massive 40% saving on your Mission to Learn subscription. Simply type in AUKIDS40 when you apply. This cuts a year's subscription down from £29.99 to just £18 and a six month subscription down from £24.99 to just £15. You can even get 40% off a monthly subscription. Go to www.njmtl.co.uk









# Teacher's New Approach is the PC Way to Learn

IT'S common knowledge that children on the autism spectrum tend to be motivated by computers. Until now, however, there have been relatively few products designed especially for children with autism. It took an enterprising special needs teacher from Surrey to spot the gap and fill it, as DEBBY ELLEY reports.



Adele Devine works as a full time SEN teacher at Freemantles school in Surrey, a school for children with autism. She teaches a class of eight autistic children. Having always been interested in finding out what motivates her pupils, she has often looked at new ways of capturing and focusing their interest. A few years ago, she realised that an idea had been staring her in the face all

"When I was in the classroom, I didn't have the resources I needed and I used to spend ages and ages finding certain pictures of things my pupils liked, cutting them all out and laminating them. That takes a long time and was exhausting," she explains. Then she started to think about her pupils' strong attraction to computers. The fact that her husband Quentin was a programmer and web designer prompted a flash of inspiration.

In a demanding schedule that combined her full-time SEN role with being the head of a brand new enterprise, Adele teamed up with Quentin to create six educational computer programmes designed for children with autism. The idea was that all teachers could make use of it to help their pupils, whether or not they worked in a specialist setting. Parents could also use the programmes to extend learning to home life.

"We wanted something that could save teachers a lot of time but also incorporate all the training that special needs teachers have into something that teachers or parents without that training could also use," says Adele.

The result is a series of fun programmes that can either be downloaded on a subscription basis or purchased individually as CD-ROMs. The programmes, based on well known children's stories, have four levels catering for different abilities and work alongside P-Scale quidelines (the government's standard

curriculum scales for special needs children). As the children progress through the levels, questions become more complex. The programmes can be personalised, and children who complete a level are rewarded with their own certificate.

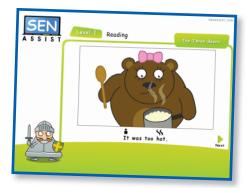
The advantage of having different levels, says Adele, is that pupils don't realise that the level of the questions they're being asked is being tailored to their own needs, so feel a tremendous sense of achievement when they have completed a level.

So far, the packages have been well received by teachers. Vanessa Whitney, an SEN teacher from Hampshire who works in the Key Stage 2 specialist centre at Stepgates School in Surrey, says: "The Three Bears has been fabulously motivational for my KS1 group of children;

they loved the control of choosing their own character and the knowledge that they could make it move by completing their tasks. The children love to interact with the computer and, as the layout is so clear and concise, they are constantly

It's been hard work, but rewarding for Adele and her husband.

Quentin says: "Hopefully the hours we have spent will save hours of teacher time and allow students the individual education they deserve."



### **Further Information**

If you want to find out more about SEN
Assist's games, look up www.senassist.com
where you can see a demonstration and take
advantage of a free trial of The Three Little Pigs game.

As well as The Three Little Pigs, programmes include The Three Bears, The Gingerbread Man, Red Riding Hood, Billy Goats Gruff and Jack and the Beanstalk. You can buy full online access to the entire group of six stories for  $\mathfrak L99$ . CD-ROMs of each story retail on the site at  $\mathfrak L49$ .





### The Three Little Pigs

My son Alec has a touch screen monitor at home and we interrupted his daily visit to www.poissonrouge.com to introduce him to SEN Assist's Three Little Pigs game.

Adults can flit between areas of the game using hidden buttons, but children are kept focused with a relatively simple screen. After choosing the level you want to work on and your own cartoon 'motivator', you can follow the story first and then answer questions on it in one of six sections. You're required to score three ticks before moving on, which means that the child needs to consistently understand what they're doing before they start the next section.

The games start with matching. At level one, it's just a question of being able to recognise the main characters in the story. By level four, children are required to match all the words in a sentence, so you can see how the game builds in huge scope for progress.

Sequencing, spelling and comprehension are then covered in separate sections. Understanding of prepositions and pronouns is also cleverly graded.

Alec didn't immediately realise that the programme wasn't his entertainment roadshow and that it required him to actually do some work. In a classroom setting, though, where it's a question of either sitting at a table and being quizzed with laminated cards, or having a play with teacher at the PC, I'm pretty certain which he'll prefer! A great educational tool.

**Debby Elley** 

## Competition

We have copies of The Three Little Pigs on CD-ROM to give away to four lucky readers. All you have to do is answer this question.

## How many games are currently available from SEN Assist?

Send your answer to us at aukidsmag@gmail.com or on a postcard with your name and address to AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE no later than February 25th.

Good luck!

## Therapies



## Which Way Now?

In the months after diagnosis, it's common to embark on the search for a Holy Grail - the one therapy programme that will provide the 'answer' to your child's autism. It feels like there is so much at stake. There are so many claims, so much hype ...it's not only confusing, it can be quite frightening, too.

Most programmes focus on one or two common therapeutic techniques which we detail below. Our rough guide is by no means comprehensive, but it's a start. At first, we'd encourage you to adopt a pick 'n' mix approach. It's the technique used and not the therapy programme that delivers it that counts.

The techniques that are best for you will depend on your child's condition, the nature of their personality and different situations. Because of this, it's always difficult to prove scientifically that a particular method is universally effective. When all is said and done, it can sometimes be down to trial and error, and finding a range of techniques that work with your child is something that develops over time and improves with experience.

## Decisions, Decisions...

Assess the risk of a therapy first. If there's no downside, then there's little harm in giving it a go, although make sure that you give a technique time to succeed before you write it off. Be cautious to jump quickly to drug or diet interventions without good guidance first from your paediatrician.

Make sure that any therapy you use does not come at the expense of your family's emotional well-being. Quality time with happy children is the best therapy of all.

Always adhere to the advice of your paediatrician.

Don't be guided by people who 'swear' by a therapy's success. No two children on the spectrum are the same. Anecdotal evidence of one child's success should not be a replacement for sound scientific research.

Decisions can be changed. Don't put pressure on yourself to get it right first time. Don't feel a failure if a technique or intervention doesn't seem to be working it just may not suit your child.

1

Watch your child.
Are they happy when
you use the therapy? Are
they responsive and is there
progress? If they're not
happy after they've got used
to it, then whatever the
hype, go with your gut
instinct.

3

Some therapies
may not suit your child
now, but may well be
worth revisiting in the
future, so don't be
disheartened.

5

As a general rule of thumb, we'd always advise checking out the credentials of anyone who offers a therapy. Make sure that a therapist is trained by an approved body in their field.

7

Be very cautious
about handing over a lot
of cash for an unproven
remedy that doesn't offer
you a free trial and carefully
consider the risks and look
at research before you
try a new therapy.

Q

It may be an idea to see whether your child responds to a certain technique well before committing to a programme that uses it exclusively.

## Scientific FACT or Science FICTION?



Professor Jonathan Green is Professor of Child & Adolescent Psychiatry in the University of Manchester. He is also Honorary Consultant Child & Adolescent Psychiatrist at Central Manchester and Manchester Children's Hospitals University NHS

Trust and Manchester Biomedical Research Centre. Here, he gives advice on how to evaluate the huge amount of research you'll come across.

New treatments for autism are constantly emerging - often involving great claims of success and families' commitment of large amounts of time and money.

How to decide then what may be useful before choosing? The Internet is full of conflicting advice and individual testimonials can be misleading. In the end, scientific research into the effectiveness of treatments is the best guide - and this is actually generally no more than the careful application of logic and common sense. Here are some of the questions that researchers bear in mind.

Was this research done with a reasonable number of children and families? This is because you can't generalize the results on the basis of just one or two cases - individual testimonials can be inspiring but may be misleading. It is difficult to conclude much from reports of under about 30 cases.

Do we know what kind of children were treated? If the results are to apply to your child, the study needs to have been done on children like yours - decent research should be clear on the nature of the children studied.

Was there an equivalent group of children studied as a comparison who were not given the treatment? This is crucial, because it is impossible to separate out the specific effects of a treatment from other factors - or general growth and development - unless there is a comparison group in the study. It is really important that the comparison group is as similar to the treatment group as possible - and that can be tricky to do. This is the reason why the 'randomised allocation trial' is so good - because by randomly allocating children to get the treatment or not before the study starts we avoid biases in selecting the groups, and we get the best comparison.

What outcomes of the treatment were measured? Are they ones that are meaningful to you or your child?

Were the people rating the outcomes 'blind' to whether the child was getting the treatment? We do this because there is a natural (and very strong) tendency for people's observation of improvements to be influenced by their hope and expectation that there will be an effect. If we want to be sure that the treatment really is effective, and not that we just hope it is, we need to have at least some of the observations of outcome done 'blind' in this way.

Has the evidence been published in a scientific journal - or is it endorsed by trustworthy sources such as the National Autistic Society? This is a good shortcut because evidence is not generally published now unless it meets the points listed above.

Do the people making claims of effectiveness have a 'conflict of interest'? In other words, might they stand to benefit in some way (e.g. financially) from the treatment being taken up? If they do, this should make you look particularly carefully at what is claimed.

But scientific research is too slow in getting answers - my child needs help now.....! That is so true and I completely sympathise - all I can say is that the pace of research into treatments really is picking up faster now. We will get the answers in the end if we can keep doing this work - and in the end that depends on funding from charities and Government. In the meantime, it may be best to do what seems appropriate, simple and obvious - to get the basics right for your child first before spending time and money on unproven treatments.

### A (Very) Rough Guide To Therapies

These are the common techniques used in special schools around the UK. The list isn't comprehensive. Most conventional education programmes do use approaches from one of the following four categories, though.



Derived from early developmental theory and psychologists such as Piaget, these approaches focus on encouraging typical development by helping the child to fill in the social gaps that they've lost. The therapy is usually led by the child. The child doesn't experience it as 'therapy', but as play.

The adult/therapist follows the child's focus, showing interest in the child's choice of activity or toy. Any behaviours, sounds and actions produced by the child are copied by the adult, showing them that these have meaning.

Key actions and sounds are copied by the adult many times and the reinforcement of them helps to shape intentional communication. Adult demands such as giving directions and asking

questions are kept to a minimum. Play is based on the child's agenda and so the child is motivated to focus on the communication.

**Especially good for:** Developing meaningful communication and appropriate use of language.

There are a number of child-led programmes which are based on this developmental approach. For more information on these specific programmes go to:

Intensive Interaction: www.intensiveinteraction.co.uk Son-Rise/Options: www.autismtreatmentcenter.org DIR/Floortime (In the US): www.floortime.org



This type of approach comes from early learning theory and behavioural psychologists such as Skinner. Therapy is mainly 1-1 instruction and activities are adult led, breaking down skills into small, achievable steps. Therapy is structured and uses motivators to reward the child after they give

appropriate responses. Generally known as Behavioural Modification, the programmes that use this approach with



children with autism are more commonly called Applied Behavioural Analysis (ABA) or Lovaas Therapy.

This therapy uses what's known as an ABC approach i.e. instruction from adult (Antecedent), response from the child (Behaviour) then reward given (Consequence).

One of the main techniques used in behavioural modification therapy is 'backwards' and 'forwards' chaining. This is when you divide a task such as getting dressed into a number of bite-sized chunks, then do all but the last or first step for the child, slowly withdrawing support from each bite-sized chunk, until the child is performing a task for themselves.

**Especially good for:** Learning self help skills and managing behaviour.



Visual approaches work on the theory that children with autism learn easier with visual support. Many children with autism have language processing difficulties and information presented visually in the form of pictures, photographs, objects or symbols are permanent and provide more obvious clues to instructions.

The following programmes and strategies can make use of a child's visual strengths:

- TEACCH Treatment and Education of Autistic and Communication related handicapped Children was developed in North Carolina by Dr. Eric Schopler. This approach focuses on using visual support to help organise the physical environment. For more details go to www.teacch.com
- Social Stories developed by Carol Gray, A Social Story™ describes a situation, skill, or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format. www.thegraycenter.org
- Comic Strip Conversations also developed by Carol Gray. This is a conversation between two or more people which uses simple drawings. These drawings explain on-going communication, providing extra support to those who may struggle to understand the quick exchange of information which occurs in a conversation.

**Especially good for:** Visual support helps to generalise skills learnt across contexts and promote independence.

• The Picture Exchange Communication System (PECS) is another visually based therapeutic approach commonly used with children with autism with limited or no language. PECS teaches students to exchange a picture of a desired item with a communication partner, who immediately responds by handing over the desired object and saying the word. For example, if they want a biscuit, they will give a picture of "biscuit" to an adult who directly hands them a biscuit and says "biscuit". The intervention then goes on to teach discrimination of symbols and how to construct simple sentences. For more information go to



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Given the special requirements of autistic children it can be difficult to find a babysitter that you feel comfortable with, someone who understands them and has the experience of working with them. This is where Time can introduce you to people who have already been reviewed and who have experience of and an interest in working with autistic children.

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Web: www.timebabysitting.com

www.pecs.org.uk

Throughout special schools in the UK, PECS is commonly used alongside Makaton, a simple form of sign language which parents can easily learn and teach to their children. (www.makaton.org)

The advantage of PECS is that it gives children the skills to form intentional communication. This means that when verbal ability does develop, the skills are already in place to make the most of it.

**Especially good for:** Developing basic communication, i.e. requesting needs and wants.



Sensory Integration is a therapy approach offered by occupational therapists specializing in sensory processing difficulties. Many children with autism have difficulty in the way that they process the outside world using their senses, appearing under or over-sensitive to sounds, sights, smells or touch.

Whilst an over or under-sensitive nervous system can't exactly be reset, it can be helped to adapt if the child is provided with different types of sensory experiences in the right way. Therapy usually involves activities that provide tactile [touch], proprioceptive [body position sense] and vestibular [body movement sense] stimulation.

Sensory integration therapy, if it's done correctly, helps the brain to become more organised, and the child to focus better. For more info go to www.sensoryintegration. org.uk

Especially good for: children who have difficulties managing their own sensory systems, usually evident through their behaviour.

### **Summing Up**

We've said that our guide is not comprehensive. There are plenty of techniques out there that are reported to have outstanding results in individual cases, although research on them has until now been inconclusive. They include biomedical and diet interventions and cognitive interventions such as RDI®

(Relationship Development Intervention), each of which deserve a separate article in themselves. The temptation is to try it all. In reality, this is a long road and you've got years to give various techniques a go.

Start simple, don't look for easy and quick answers, and maintain a critical outlook when faced with outlandish promises.

## Reviews



### BOOK What to Do When Your Temper Flares

By Dawn Huebner 2007 Published by Specialdirect.com Available from www.specialdirect.com

£14.50 ISBN 9781433801341

Using a cognitive-behavioural approach that aims to change thoughts, which in turn changes feelings and behaviour, this interactive book is designed to be shared with your child, discussing strategies along the way.

It contains exercises and drawings and uses simple language and clever metaphors. Anger 'dousing' techniques include taking a break, thinking 'cool' thoughts, releasing anger safely and problem solving. The reader is also taught to recognise 'sparks' for anger.

A valuable resource for the over sevens on the higher end of the spectrum with a good understanding of language.

Tori Houghton



### BOOK Social Situation Stories

By Alison Harris
2010
Published by
Specialdirect.com
Available from
www.specialdirect.com
£17.99
ISBN 9781906213312

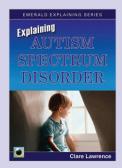
Social Situation Stories, written by Alison Harris, is aimed at kids aged between five to 11 and is packed with great, simple stories that can be adapted to suit your child. The classroom ones are pure gold dust to any learning support assistant working with a child who has autism.

The author, a paediatric occupational therapist, has obviously thought through the school day from an autistic child's viewpoint, giving a very thorough collection of social 'situation' stories to take a child through each potential sticking point in an average school day.

These types of stories offer plain, simple and factual guidance on social situations to prepare a child with autism for different experiences and to help them understand what is expected of them. If you help a child in this way early, then learned behaviour eventually becomes adapted and natural.

If your child is in a mainstream setting and the teachers aren't quite sure about writing their own material, I'd recommend that you buy this pronto - they'll certainly welcome it.

**Debby Elley** 



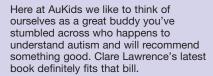
#### **BOOK**

### **Explaining Autism Spectrum Disorder**

By Clare Lawrence 2008 Published by Emerald Publishing £9.99 ISBN 9781847161642 Clare beautifully summarises both traditional and contemporary research in the sort of nutshell you can only construct if you truly understand something. It's such an accessible read that you could also dish it out to the family, or anyone else who takes an interest but doesn't want to be bogged down with heavy material.

My only quibble is that the front cover isn't nearly as promising as the material inside.

Debby Elley



Its author, also a parent of a child with autism, combines an easy reading style with humour to bring you a detailed overview of what autism is and its implications for a person with the condition. Then it moves on to offer some great practical advice.

## \* Giveaway

We loved it, so of course we had to bag some copies for our readers!

We have three copies of Explaining Autism Spectrum Disorder to give away to the first three readers to be picked out of the hat after February 25th. Send your name and address to AuKids, PO Box 259, Cheadle, SK8 9BE or drop us a line at aukidsmag@gmail.com



#### **BOOK**

### The London Eye Mystery

By Siobhan Dowd 2008 Published by Corgi Yearling £5.99 ISBN 9780440868668

Siobhan Dowd's award-winning novel centres on the disappearance of a teenage boy, Salim, who seemingly vanishes into thin air whilst on board the London Eye - hence the mystery. Our hero Ted, who is Salim's teenage cousin, alongside his older sister Kat, tries to unravel the puzzle and in

doing so stays one step ahead of the story's real detectives.

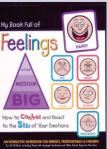
Ted's secret weapon is his high-functioning autistic brain, which allows him to problem solve in an eccentric but effective manner. His brilliant lateral thinking, combined with an obsession with weather systems, eventually leads to some clever deduction.

As the story unfolds, Ted, our narrator, reports faithfully on the constant battle inside his mind to decipher people's expressions and what they mean by everyday idioms. Neurotypical readers will end up full of admiration for our young hero and his immense efforts to overcome the social limitations of his condition.

A heavy helping of wit and warmth make the novel a buoyant and uplifting read and a must for anyone connected with autism.

Debby Elley

### BOOK My Book Full of Feelings

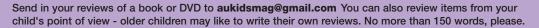


How to Control and React to the Size of Your Emotions By Amy V. Jaffe and Luci Gardner 2006 Published by Specialdirect.com Available from www.specialdirect.com £23.94 ISBN 9781931282833 This practical book contains worksheets and activities to address and modulate six feelings - happy, sad, angry, frustrated, worried and calm. Based on comic strip conversations originally introduced by Carol Gray, each emotion is visually represented by a different colour and the degree/level of emotion is showed by degrees of shading. The idea is to think about an emotion in terms of size and to give examples for each one.

It's practical and useful and the colour coding works well, but the book would benefit from some blank sheets for readers who want to introduce their own colour-coding system.

Tori Houghton





## The Last Word



I don't always broach the subject that my twins have autism, but when I'm asked what I do for a living ('living' is rather an optimistic term given that Tori and I aren't on salaries for this yet) it's hard not to. Writing a parenting magazine on the subject does rather give the game away.

So then I am faced with the challenge of communicating to people that the headline may look frightening, but that the small print underneath it reads rather differently. Of course, I've got to do this in a two-minute nutshell and without seeming like some sort of disability evangelist, and preferably before the lay person passes out with

Most people adopt the 'oh god that's awful' look straight away, probably thinking that I'm looking for some sort of sympathy. It doesn't annoy me, because I'm used to it and they mean well, but it does mean that the 'nutshell challenge' has become rather well honed over time.

I'm naturally quite a positive person, but there's lots of other reasons why I feel it's important to convey autism in a good light. If I were to constantly say how difficult my kids can be, apart from making the listener tune out rather quickly I'd be bound to internalise that message to the extent that I treated Bobby and Alec as difficult even when they weren't being particularly challenging.

I do of course moan about them sometimes, as we all do about any children, but not to outsiders because it's not how I like to define my life.

Truth is a shape shifter. It's not an absolute but varies on your perspective. So if I said that Alec was non-verbal, severely delayed and dices with death pretty regularly, then that would be true. Alec isn't just those things, though, he's a giant cuddly teddy bear of a boy, thoroughly affectionate and full of joy. I'm proud of who he is, and what he's overcome, and that's what I choose to communicate to myself and to everyone around me. My jokey column isn't a work of fiction, it's just how I see us.

I've been encouraged by realising that this changes the way in which people deal with me, and more importantly the way that they deal with Bobby and Alec. They become the twins' champions, because I am. And let's face it, if you don't tell the world that your kids are great, no one else is going

## Why Being **Positive Is Always A Plus**

By Debby Elley, journalist and mum of twins with autism.

The other reason I remain positive about them is for the twins themselves. I think about how I'd react if my behaviour, which I couldn't help, were being treated as a nuisance rather than something to be understood. I think I'd feel pretty rubbish, and that would have a profound effect on my happiness and my behaviour.

One parent told me that she was nervous of getting a diagnosis in case having autism on an application form spoiled her son's chances in life. This is a perfectly understandable concern, until you consider that as a parent you can play a role in your child's understanding of their own condition, and the way they see themselves, starting from now.

I've no problem with Bobby convincing a future employer of the benefits of employing him (if he can stop talking about Super Mario for long enough). That's because he has a clear understanding that he's brilliant. I know this because on his last school report, looking back on what he'd achieved during the year, he sensibly claimed: 'In Year 1, I have become the ultimate champion of everything'.

A bit braggy, yes, but I'd rather that than he felt any less of a person because of his condition. And as he combines his confident swagger with charm and good humour, it's not made him obnoxious. Well not yet anyway, ask me when he's 15.

Alec, on the other hand, as I've already established in this column, will probably not be a top lawver and may not have to impress an employer (although, staying positive, you never know...someone out there may need a trampoline tester). How he sees himself, though, will still be a major factor in his future happiness - and mine.

When I'm short-tempered with Alec, or his behaviour is getting on my nerves, he seems to absorb it like a sponge and becomes more challenging. In fact, he seems to absorb non-verbal messages even more than his higherfunctioning sibling. Conversely, when I'm feeling mellow and emitting lots of little non-verbal love hearts in his direction, Alec seems as good as gold. The formula isn't always quite like this,

but enough to be noticeable. Staying positive isn't just a mantra for me, something that I feel I ought to do in order to put on a brave face for the world. It goes much deeper than that, and the more I do it, the more positive Introduce a friend to AuKids magazine and get FREE entry to the play zone at Mr Clown's!



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# Celebrity Spotlight

Readers' Page



Elliot Brady
aged 7

# Gregor Roden Aged 6

Diagnosis: Autistic Spectrum Disorder.

My family: I live with my mum, dad and little sister Kirsty who is two.

School: Aberlady Primary School, East Lothian.

I love: Cycling, cartoons, climbing trees, playing on the computer.

I hate: When the TV goes 'scratchy' or when things make unexpected noises.

Song that describes me: Some of the lyrics from I Am What I Am eg. "I bang my own drum" and "Why not try and see things from a different angle?"

My personality: Non-conformist, original thinker, fun-loving and very determined.

My ambition: Would like to appear in a



FIXED IT FOR ME Jimmy Who?

AuKids has fixed it for Gregor to be a cartoon - voila!

Diagnosis: Autism.

School: Northenden Community School (mainstream), Manchester.

I love: Carrots, football, swimming, being outdoors, watching planes, the Wii, Nintendo DS XL, computers and to make new friends.

I hate: Unexpected loud noises.

Song that best describes me: R Kelly - I Believe I Can Fly.

My ambition: To be a pilot for Monarch Airlines and to fly a plane.

If I were Prime Minister: I would ensure schools were adequately funded for people like me.

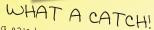
Want your little star to appear on our Celebrity Spotlight page? Send your own answers with a jpeg picture of your child in action to: aukidsmag@gmail.com

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### WORLD OF WONDER

The Makaton Charity has been working with the V&A Museum of Childhood near Bethnal Green in London, which has created a display called 'Welcome to Our World ... Living with Autism'. This thought-provoking new display explores life through the eyes of children with autism and is open until March 19th 2011. Admission is free. To find out more, look up www.makaton.org



Potty training can be a trial at the best of times, but without a downstairs toilet, taking them every half hour can be tricky The Happy Pee is a unisex canister with a froggy lid and is used for when kids get caught short on journeys. It's ideal for storing under the stairs as a very mini toilet. Buy one at www.presentsformencouk

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