

# Autkids

Issue 11  
Spring 2011  
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Positive Parenting for Children with Autism Spectrum Conditions



## Maps the Way I Like it!

The Upside of Autism



**Championing our Children**  
NAS Chief Executive Mark Lever on Turning the Tide



**Repeat After Me...**  
Our panel discuss echolalia

# Letter from the Editors

## 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.

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## Time

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Web: [www.timebabysitting.com](http://www.timebabysitting.com)

## Hi and welcome to Issue 11!



Co-Editors: Debby Elley and Tori Houghton.

Now that we have a new website up and running, you'll be able to enjoy extra benefits from your subscription. If you visit us at [www.aukids.co.uk](http://www.aukids.co.uk) you can hook up with other members. No one will be given any direct contact details and it's all completely secure.

You can use the website to seek other readers in your area in similar circumstances, just make sure that you select the 'share details' option under your contact options in 'my details'.

There's also up-to-date news on the site and other features, so plenty to keep you entertained whilst you're waiting for the next issue to pop through the post.

One other feature you'll love is the opportunity to delve into the archive and catch up on past issues. This is only available to subscribers and we're not charging any extra, but if you do have a little read, we'd love it if you'd send us a donation (using the handy new donation button online). Every little helps, and AuKids still needs plenty of help to remain afloat! Also, you can use the website to sponsor Peter Lawson of Cygnet Health Care, who is doing a half-marathon for AuKids in May - see News page. Go Peter!

Whilst we're talking cash, a quick reminder that if you send off for a Just Giving debit card (works like any top up card), AuKids can benefit from a percentage of the amount you spend at well known outlets such as Sainsbury's, Debenhams, Asda, Argos, Boots and B&Q to name just a handful.

Well that's the science bit, now onto this issue. The chief executive of the

National Autistic Society, Mark Lever, is in the hot seat answering questions about how the organisation is tackling issues relating to our kids. We loved finding out about famous people with autism for our front cover feature. Plus, there's some great information on echolalia.

Finally, it's probably worth us telling you about the adverts you'll read in the magazine and on our online banners. AuKids isn't bursting with adverts as we reckon you would far prefer to read articles instead. We don't rake it in with advertising revenue either, which is why we aren't a very rich magazine!

However, the small number of advertisers that are given space have been given the rubber stamp by AuKids. This means that we either have direct experience of the products or services ourselves, or we have spoken to a parent who would recommend it to others. In other words, we don't just let anyone advertise.

We do not, as a matter of policy, endorse specific clinical remedies or therapy programmes, because we like to remain impartial. So you can trust us. If you really like that policy, then please excuse our shameful hints about donations!

If you like the magazine, please tell others about it and do feel free to ask us for leaflets if you know of a place that would welcome information on us.

Enjoy!  
**Tori and Debby**

**The winners of Issue 10's competitions were:** Gillian Levis, of Lisburne School, Stockport; Faygie Halpern of Salford; Viv Hancock of Stroud, Claire Smyton of County Tyrone, Northern Ireland; Lorraine Gason of Norwich and Marcia Hamlin of Stevenage. Well done to all of you!

Our front cover star is Delta Worts - see Page 4.

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

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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](http://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.**

## AuKids Reader Witnesses Autism Bill Passed in Northern Ireland



1. Arlene Cassidy, CEO of Autism NI 2. Dominic Bradley, Chair of the All Party Group for Autism  
3. David Heatley, Chair of Autism NI 4. Dr Claire Hughes, Chair of Lisburn branch of Autism NI  
5. Paula McCClinton, Lisburn branch secretary 6. Arlene Hewitt, Lisburn Committee member  
7. Anne Hayward, Lisburn branch fundraiser

One of AuKids' subscribers, Paula McCClinton, is also the secretary of the Lisburn Branch of Autism Northern Ireland. She had the privilege of being present at Stormont to witness the Autism Bill for Northern Ireland being passed by the Northern Ireland assembly on March 16. She wrote to AuKids to say:

*"The Bill will give autism recognition as a social and communication developmental disorder under the Disability Discrimination Act and will help ensure that people with autism have access, through an inter-departmental Autism Strategy, to the services they require throughout their lives. After many years of hard battling we have finally made it!"*

Chair of Autism NI, David Heatley, added: "On a truly historic day the Autism Bill was voted through the final debate with none of the MLAs (Member of the Local Assembly) opposing the Bill. The Bill gives the broadest legislative protection in the United Kingdom and Ireland with a cradle to grave approach. Special thanks must go to Dominic Bradley who chaired the All Party Group for Autism and the MLAs from all parties who supported it."

The Bill was the result, he added, of a long and successful lobby on the part of Autism NI, led by CEO Arlene Cassidy for almost ten years. Mr Heatley added his thanks to parents who had joined the lobby. "Without them the battle may well have been lost," he said.

## Peter Runs For AuKids Cash

AuKids is delighted to announce that Peter Lawson of AuKids sponsors Springside Services will be running the White Peak half-marathon in May to raise funds for the magazine.

Peter is the services manager at the Stockport branch of Cygnet Springside, an organisation providing specialist autism residential and outreach services.

Cygnet Springside opened its North West operation at around the same time that AuKids magazine was launched and the two operations have watched each other with interest ever since.

In 2009, when Peter spotted himself in a photo in AuKids (see above), he was shocked by his weight and decided to do something about it.

He enrolled in Slimming World and embarked on a healthy eating and running regime. He enjoyed running so much that it became a hobby, and he started to run marathons in aid of organisations that were close to his heart.

By 2010, Peter had made the headlines and was on GMTV after the press heard about his dramatic weight loss - from 25 stone to 12 stone in just under 12 months. Even Tori and Debby failed to recognise him at a meeting and were waiting some minutes for Peter to arrive before they realised that he was in fact sitting opposite us!

Peter became involved in raising funds for the Parkinson's Society after he lost his mother to the disease in 2005. He has run three half-marathons for the society at Meerbrooke, Leek and Macclesfield.



Peter as he is today, running for charity. ▲

◀ The 2009 photograph of the Springside team in AuKids magazine that inspired Peter to follow a weight loss campaign.

This year, Cygnet Springside became one of our sponsors. Peter said:

"I have decided to run for AuKids because it is an exceptionally informative, well produced and fun magazine, developed by people who have a real understanding of autism and how individuals and their families can be affected by the condition.

"We want to do anything we can to help the magazine's publication to continue."

Co-editor Debby Elley said: "This is fantastic news, we are so touched at Peter's commitment to our project."

### Sponsor Peter!

To sponsor Peter and raise cash for AuKids, you can donate online at our website. Look up [www.aukids.co.uk](http://www.aukids.co.uk)

## Ready to Roll...



Oily Cart, a theatre company specialising in performances for young people with disabilities, is taking its production of DRUM to the Unicorn Theatre in London from April 19-May 8. The multi-sensory and interactive show is designed for children aged between three and 11 with complex disabilities.

For the first time, a version of DRUM designed especially for kids with an autism spectrum condition will be staged. Call the box office on 020 7645 0560 for details. The Unicorn Theatre is situated close to Tower Bridge and is a purpose built modern setting for young people. Oily Cart often tours special schools. To join the mailing list, go to [www.oilycart.org.uk](http://www.oilycart.org.uk)



For more news, visit the news page on our website at [www.aukids.co.uk](http://www.aukids.co.uk)

We spend a lot of time at AuKids focusing on how to help a child with autism overcome some of the limitations caused by the condition. Well, call us self-indulgent but we thought it was time we waved the flag for the upside of autism. Not everyone with autism has a special talent and not everyone with autism can use an interest to their advantage. Yet people on the spectrum have enjoyed tremendous achievements. It can be a passionate interest that drives them. Sometimes it's the finest attention to detail, endless patience and lateral thinking that sparks success. Some people with autism have astonishing memories. Here we celebrate what happens when being different **MAKES** the difference...

## Artist: Rose King

(known as Rosie)

Twelve-year-old Rosie King's enthusiasm for drawing was a big bonus when her mother Sharon decided to write a child-friendly novel to explain autism in a colourful way. Rosie, who lives with her family in Wakefield, has Asperger's. Her talent and insight helped her to interpret the book's theme in a creative way.

The Daily Journal of Arabella Crumblestone (from sharonkingbooks.co.uk) is a fairy story in which a sprite finds herself far from home and relies on two children, one of whom has autism, to help her find her way back. The



**Dynamic Duo:** Rosie and mum Sharon pose with their new book.

characters in the story are based on Sharon and Richard King's three children. Rosie is depicted as Faith in the story. Brother Lenny, eight, and sister Daisy, ten, who has Kabuki Syndrome (a rare genetic syndrome), also appear as characters in the tale.

Rosie's mum Sharon tells AuKids: "Rosie was illustrating the book as I was writing it, because she really liked the story. Her drawings were just right and once I had seen them I couldn't imagine the characters any other way. What she lacks in finesse, she really makes up for in enthusiasm. I love children's drawings, anyway, they lack inhibition and fill the page with an innocent energy that people tend to lose as they get older."

Rosie tells us: "I started drawing when I was really little. I used to draw the same picture over and over again. I remember when I was in reception, I drew a tiger for the teacher. She said it was really good, she showed it to the class and I felt very proud."

Rosie's definition of autism is "a type of awesomeness."

She says: "Having Asperger's can make you very, very clever. I don't feel restricted by Asperger's. My friends never mention it, though they know I have my own specific ways and if they are good friends then they understand about that. The friends just get to know the person that I am."

Sharon adds: "People have been so positive about the book. Everyone agrees that I was right to use Rosie's drawings. As it was a book for our family and about our family, it was really the only choice!"

"Being a professional illustrator has meant the world to Rosie. She has learned through the experience that anything is possible, and nothing need hold her back. I am sure that despite and in some ways because of her condition she will go on to great things. She has a very individual take on life, and even though some small things seem to cause her problems, the big things (the things that most children would find incredibly scary) do not seem to faze her."

So, where will Rosie's talents take her in the future? "I would like to be a comedienne/actress with a pilot's licence. In my spare time I will draw and write about three novels. I will not marry, I would prefer to live in a caravan with a dog, possibly a Labradoodle. If my brother, Lenny, is independent enough, he might want to come and live with me."

"I don't think that Daisy would be independent enough. I will be away on business or flying aeroplanes quite a lot of the time and I don't think that she would manage on her own. I love my brother and sister just the same, though."

# The Autism



## Actor: Braeden Reed

American actor Braeden Reed, who has autism, played six year-old Alan in the 2010 film Dear John starring Amanda Seyfried and Channing Tatum. His character has the same condition.

"I am eight now and I was six when I started acting. My friend, Mr. Phil, asked me to audition and I got the part of Alan. Alan has autism like me. It made it kind of easy because I know more about autism than most kids so I think I was able to do a great job! When I was little, I had lots of help with learning and I think this helped me because I learned how to pretend real well.

"Sometimes my autism makes me worried about things, like if I am going to have fun doing the movie or if everyone will be sweet to me. I don't know what I'd say to another kid who has autism and wants to be an actor - maybe 'Good luck!'"



## Map Reader: Delta Worts

Delta Worts, who is nine and lives in Manchester, loves maps. Why? "You get to see where you are in a book," he says.

"Maps mean absolutely everything to me. When I buy a new map I always like it because I get to add it to my collection. When I look in a new map, I am excited because you never know what will be in the next page! I feel excited because if I am thinking and I have enough money, I can buy the map! So if I tell you to go to Leeds, I can show you the way! I can direct people to the exact location."

This interest has proved a great asset to Delta's family and will no doubt lead to a career in cartography.

Mum Nikki says: "I know no matter how lost I get, Delta can always get me home. I'll never need a Sat Nav!"

Turn to Page 10 to win yourself a copy of The Diary of Arabella Crumblestone



# Advantage

## When I Grow Up

Autism has given the world creativity and originality in many forms. Here are a few high profile examples...

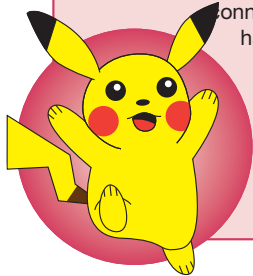
### Video Game Designer: Satoshi Tajiri

A love of insects and a fascination for video games were the sparks that eventually led Japanese game designer Satoshi Tajiri, who has Asperger Syndrome, to create Pokemon. The game was not expected to sell well, but instead sparked a multi-billion dollar franchise and reinvigorated Nintendo handheld gaming.



As a child, Tajiri enjoyed insect collecting as a hobby and he wanted his games to allow children to have the feeling of catching and collecting creatures. He became fascinated with arcade games as a teenager, though his parents worried about it. His video game company Game Freak was established in 1989 and the idea of Pokemon was conceived the following year. Tajiri pioneered the idea of

connectivity between handheld game consoles. Electronic Gaming Monthly credited him as one of the ten most influential people who made the modern video game market.



### Musician: Gary Numan

When it comes to a cool image, not many can top electropop hero Gary Numan, who enjoyed phenomenal success in the early Eighties.

During a BBC interview for the programme Synth Britannia, Gary recalled: "I was in a lot of trouble at school, I was sent to a child psychiatrist - it turned out to be, apparently, Asperger's. I felt more comfortable on my own. The classic loner I suppose, didn't go out drinking, didn't go out clubbing too much."

Being a classic loner didn't exactly hinder the image, though. In fact, the singer is most famous for 'Cars', which reached Number 1 in the UK charts in 1979. Numan once had a near miss when he escaped from a potential attack in his car. "'Cars' is just about feeling safe in amongst people in a car, because no one can get to you, you're in your own little bubble," he explained during the same interview.

**NOW:** Gary still tours and records music. The Pleasure Principle Live was released in 2010.

**THEN:** Gary Numan at the height of his fame in Newcastle, 1984.



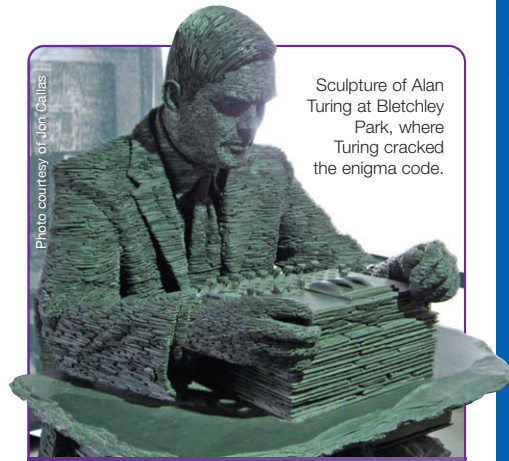
Photo courtesy of Howard Barlow FRPS.

### Computer Pioneer: Alan Turing

OBE, FRS (1912-54)

Turing, who had autism, was influential in the development of computer science. During the Second World War, he worked for the Government Code and Cypher School at Bletchley Park, Britain's code-breaking centre. He devised a number of techniques for breaking German ciphers, including the method of the Bombe, an electro-mechanical machine that could find settings for the Enigma machine. He also created one of the first designs for a stored-programme computer, the ACE.

Evolutionary biologist Richard Dawkins has been quoted on Turing: "If anyone could be said to have invented the future, it was Alan Turing. By imagining a machine that could solve all conceivable mathematical problems, Turing had invented the concept of the programmable computer years before anybody could see how to build one. The full power of his revolutionary ideas would not be appreciated for years, even decades."



Sculpture of Alan Turing at Bletchley Park, where Turing cracked the enigma code.

Photo courtesy of Glyn Callias

## Obsessions: The Upside

The word 'obsession' implies something that is utterly compulsive, negative and destructive. A compulsive interest needn't be negative, though. These adults used *Wrong Planets's* forum to tell us about their successes.

**Jocundthelilac:** "When I was about ten, I got the Harry Potter books for my birthday. Up until then, I hadn't read any literature (it was all fact books and maths stuff). It inspired me to start writing my first proper stories. I was obsessed with HP for a good three or four years, during which time I grew out of maths and started to be more interested in English. Now I'm a poet and writer."

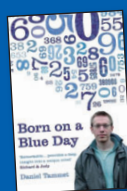
**RhettOracle:** "I discovered radio when I was in my single digits. I have been fascinated by it ever since. When my voice changed, it went deep baritone and suddenly I had the voice to do radio. Now I've been the staff announcer on three stations and I make commercials and assemble programmes on the computer. My voice is on the radio and that's pretty much what I've always wanted."

## Autism at Work

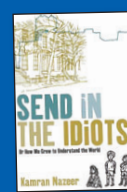
The Danish company Specialisterne employs software testers who are autistic because of their efficiency, attention to detail, focus and accuracy. Computer skills are highly transferrable and often highly desirable. So remember, today's 'obsession' could be tomorrow's lucrative career!

## Read All About It...

If you fancy some inspiring autism-related bedtime reads, try:



**Born on a Blue Day**  
By Daniel Tammet  
Published by Hodder & Stoughton



**Send in the Idiots**  
By Kamran Nazeer  
Published by Bloomsbury



**Thinking in Pictures**  
By Temple Grandin  
Published by Bloomsbury

Take a quick glance at some other distinguished names in the world of autism and check out this excellent website: [www.mnddc.org/asd-employment/2-wow-people.html](http://www.mnddc.org/asd-employment/2-wow-people.html)

Photo courtesy of Ed Fielding

# Ask the Experts

“ My daughter repeats a lot of what I say and what she hears on TV. I’ve heard about echolalia - what is it and should I discourage it? ”



**Luke Beardon**

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

Echolalia comes in various forms, but simply put is the repetition of words or phrases that a person has heard. There are various reasons for echolalia, and it is important to ascertain why your child is repeating words. Some reasons include:

- form of learning
- delayed echolalia
- palilalia
- sensory pleasure

All children go through a period of echoing speech in order to learn meaning; it is often suggested that children with autism who are echolalic are more likely to go on to use language effectively than those who do not. In such an instance it is obviously not a good idea to discourage echolalia.

Delayed echolalia tends to be the repetition of a 'stock' word or phrase - I believe that often this is an expression of an associated emotional state. For example, if the child associates the words 'sit down Jenny' with being stressed, because in the past when she is stressed she has been told to sit down, then at times of distress Jenny may repeat the phrase over and over again. It is very useful in such cases to work out the meaning behind the

words, rather than accept the words at face value; thus, Jenny is demonstrating that she is stressed - not that she wants to sit down.

Palilalia refers to the repetition of a word, usually involuntarily, that the individual has heard at the end of a sentence. Recognising it becomes very important when giving verbal choices to a person. For instance, 'Do you want tea or coffee?' may result in a reply of 'coffee', but 'Do you want coffee or tea?' may result in 'tea'. This is not a meaningful choice, simply palilalia, and it is best in such circumstances to give a visual choice.

Lastly, the individual may simply gain huge amounts of sensory pleasure from the sounds of certain words (this may be a sign of synaesthesia\*).

In summary, echolalia is not something that should be automatically discouraged; having a better understanding of the reasons behind it should help understand the individual.

\*synaesthesia - a neurologically-based condition in which stimulation of one sensory or cognitive pathway leads to automatic, involuntary experiences in a second sensory or cognitive pathway

“Sometimes I used to repeat the same words over and over as this made me feel safer”  
Therese Joliffe, an adult with autism.



**Autism in the Wild**



**Barry M. Prizant**

Director, Childhood Communication Services, Adjunct Professor, Brown University Center for the Study of Human Development, USA.

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Echolalia is repetition of speech that a child has heard. If the speech is repeated immediately, it is referred to as **Immediate Echolalia** (Adult: “Do you want to go out?” Child: “Do you want to go out?”). **Delayed echolalia** is echolalia that is repeated sometime later, and may include repetition of videos, previous conversations or songs. In the 1960s and 70s, it was believed that echolalia needed to be discouraged or even punished. Since that time, our research has demonstrated that immediate and delayed echolalia may serve important purposes in communication and in language development and

may take different forms (interactive, non-interactive, with or without comprehension). For example, echolalia may be used to take a turn in conversation if the child does not understand what was said; to request something that is offered or to say “yes”; to hold information in memory until it is understood, to direct one’s own actions or to regulate emotions (to calm oneself). What is interesting is that all children (and even adults!) use repetition of speech or inner language (thought) for the same purposes.

Echolalia should not be discouraged, as research has demonstrated that children who use echolalia make better progress in language and social communication than those who do not speak. However, we should help a child move through echolalic stages on to more creative language. In most cases, we see echolalia as a stage on the way to the development of creative, conversational language. Echolalia may be addressed by simplifying the language we use, breaking down what a child is echoing into simpler, shorter phrases and using visual supports and written language for children who are able to read.



Peter Lawson

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

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Email:

peterlawson@cygnethealth.co.uk

Echolalia is often associated with autistic spectrum conditions, although it is not exclusive to autism and can also be associated with developmental and learning disabilities. The term refers to the immediate or delayed repetition or 'echoing' of sounds, words or phrases, much as you describe your daughter doing.

As the terms imply, immediate echolalia means an immediate repetition, so, for example, if you asked your daughter 'Would you like a drink?' she would immediately respond to you with the same question. Delayed echolalia may involve more complex or longer dialogue being reiterated at different times, sometimes repeatedly, for example lines from her favourite film, TV adverts etc. She may even quote (almost verbatim) things you have said to her at earlier times.

Echolalia is actually an important part of all children's early communication and understanding development; however, as the neurotypical child develops, their learning becomes, at least initially, 'Gestalt' in nature, i.e. he or she learns that words not only sound as they do, but are linked with many sensations, emotions and outcomes. For example, the word 'balloon' may conjure up associations with shapes, colours and noises.

As the child's development continues, learning becomes increasingly analytical, leading to the ability to apply more abstract contexts to words and phrases. The word 'balloon' may therefore be

cognitively linked with parties and fun times - or flying high in the sky.

Although echolalia may appear counter-productive to your daughter's communication skills development, it is not. Rather, it is evidence of the autistic individual's way of thinking, particularly in relation to non-abstract perception. Your daughter's echolalia is a sign that she is able to learn and use language and that her communication skills can further develop; consider echolalia as a stage in her language and cognitive development.

There are several different methods in addressing echolalia. However, I rather like the Judevine Centre advice, as it can be easily applied and might be a useful starting point for you. An abridged version is as follows;

*Treatment for echolalia involves responding to the person literally. If the person echoes, "Do you want juice?" (after you have asked the question), say: "No thank you." Follow this with: "I think you want to tell me something though." Then use sign language or another visual cue to prompt the person to say: "I want some juice."*

*Similarly, if you ask the person, "Do you want a cookie? Yes or no?" and the person echoes your last word ('no'), accept this response. Say, "You said 'no', that's okay, I will eat the cookie myself." If it looks like the person does want a cookie, say: "It looks like you changed your mind, if you want a cookie, say, 'yes'". Prompt for a 'yes' and reinforce a correct response.*

**"Echolalia is a good sign because it indicates that the child's brain is processing language even though he may not be understanding the meaning of the words. These children need to learn that words are used for communication"**

**Temple Grandin, an adult with autism**

**"Bobby doesn't repeat everything you say, but he does repeat phrases from film and TV. At times, he repeats great chunks of familiar dialogue, which seems to comfort and amuse him, and his memory for it is unbelievable - he recollected word for word the entire first half of Toy Story in the car the other day. He also 'cuts and pastes' phrases that he's learnt from TV into his own social situations in quite an appropriate way. I wouldn't say it's a negative thing with us. I think sometimes he can't tell the difference between what's in his head and what's outside it, and that it's a process that helps him to make sense of language."**

**Debby Elley, mum to twins Bobby and Alec, age 7.**



Greg Pasco

Research fellow based at the Centre for Research in Autism & Education.

Greg is currently working on the British Autism Study of Infant Siblings (BASIS), and for many years was a speech and language therapist working with children and adults with ASD.

Echolalia - repeating words and phrases exactly as other people have said them - is a very common feature of the spoken language of children and adults with autism.

Depending on how much non-echoed language your daughter has, the fact that she is using speech at all (compared with the large minority of children with ASD who don't use speech to communicate) can be seen as a positive sign. Many children whose speech starts out being predominantly echolalic eventually use language in a more conventional way.

It can be hard to know how to respond to echolalic speech. It may be that your daughter

repeats what you say because she knows that she is expected to say *something* (in response to a question, for example) but doesn't know *what* to say. If her echolalic speech is mostly delayed it may be that she is trying to initiate or maintain a conversation with you, but again, doesn't know how to do this using more appropriate language. If you interpret her echolalic speech as being part of her attempts to communicate meaningfully, then you can try to respond in an appropriate way (just as we might engage a baby in a 'conversation' even though we don't really know what her babbling means).

In general, it is probably best *not* to discourage your daughter from speaking echolalically - she may misinterpret this as meaning that she should not speak at all. If her echolalic speech does not appear to have a communicative function, it may be that she just enjoys the predictable nature of the repetition (or your response to her repetition). If this is the case you may feel that it is best not to respond or react after the first two or three times she says something. If her echolalic speech occurs when you are offering her a choice (You ask, "Do you want apple or orange?" - She replies "Apple or orange") you could try offering the choice non-verbally - by holding up an apple and an orange and letting her choose by pointing to or reaching for the one that she wants.



Do you have a question for Ask the Experts? E-mail us at [auidsmag@gmail.com](mailto:auidsmag@gmail.com)



My Town Tiggers Annual  
**Autism Conference:**  
**“Research, Reality &  
 ROCK N ROLL”**

27 May 2011, 9.00am—4.30pm, Hilton Hotel, Blackpool



**Keynote Speakers:**

**Professor Simon Baron-Cohen, Dr Glenys Jones,  
 Professor Jonathan Green and John Clements**



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 and young people  
 with Autism**

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**Enter Our**

**Prize Questionnaire  
 and Get Quoted in Our Book!**

**The AuKids Team is writing a book - and we need your help.**

Yes, fame awaits you. Earlier this year Tori and Debby met up with two commissioning editors who have asked us to write a book aimed at families and friends of a child with an autism spectrum condition. We see this as an opportunity to write a beginner's guide for anyone who is completely new to autism.

We are still in the very earliest stages of preparation but we'd like our parent readers to be a part of our book by sharing your stories, your thoughts and your feelings.

We'd also like you to pass the second half of this questionnaire to someone you know who has made a difference to your life since your child was diagnosed. They can be a relative, a friend or simply someone who has had professional involvement with your family.

We know you don't like to ruin your precious magazine (!), so please fill in your answers on separate sheets of paper (just make sure the question

numbers are accurate) and send to us at AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE.

If you prefer, you can fill it in online at [www.aukids.co.uk](http://www.aukids.co.uk) You don't have to answer every question - whatever you tell us will be appreciated.



Every questionnaire received between now and our next issue will be entered into a prize draw to win an **Animal Flash Pad** from our friends at The Sensory Toy Warehouse. This is an electronic touch, lights and sounds game board for ages six and up. It's touch sensitive, featuring 16 multi-coloured LED lights

and exciting sound effects. Bound to be a hit with sensory seekers! In short, the business, and worth £24 - so be in it to win it! Look up [www.sensorytoywarehouse.com](http://www.sensorytoywarehouse.com) for more info.

**By taking part you and your friend/relative agree to any or all of your answers being used in the book. We may choose to contact you to find out a little more, too. Thanks!**

**Questions for you**

(BLOCK CAPITALS IF YOU'RE HANDWRITING IT, PLEASE):

- 1 Your name
- 2 Your child's name and age
- 3 Your city/town
- 4 Can you think of someone who has supported you since your child was diagnosed? Tell us what they did to make a difference to your life. Tell us who they were, what their relationship is to you and try and share with us a particularly good memory of when they helped out. Simple memories are as powerful as special ones. You can write about their effect on you, their effect on your child, or both. Comment on attitudes as well as/or actions.
- 5 Now, we promise to keep you anonymous for this one! Can you share with us an example of where things have gone wrong because either a friend or a family member did not understand your child or your circumstances? What could this person have done to make things easier for you? Tell us their relationship to you, but we will keep your identity secret.

**Questions for your relative or close friend**

- 1 What have you found valuable in helping you to understand the child you know who has autism?
- 2 Were there any 'light bulb' moments when you felt you understood what this child or family needed from you?
- 3 In your position as a friend or family member, what would you like to have known more about after diagnosis?
- 4 Knowing this family as well as you do, what has been hard for you?
- 5 Have you any wisdom that you'd like to share with others who have a close friend or family member in the same situation?
- 6 What have you learnt from the experience of having someone close to you affected by autism?

Finally, if you are happy to be contacted about any of your answers, please supply us with a telephone and/or e-mail address for both yourself and your friend/family member.

*Many thanks. You've just done your bit to educate the world in autism!*





# ON THE SPOT

## Mark Lever

Chief Executive of the National Autistic Society



### Cuts are having a direct effect on autistic children, with speech and language therapy one of the highest profile services that has been hard hit in certain areas of the UK. What is the NAS doing to help parents facing cutbacks in autism services?

The cuts are going to affect everyone, with all services being targeted. The important thing for all of us is to ensure that the most vulnerable in our society are least affected - and this includes the many thousands of families affected by autism who are struggling to get even the most basic of support.

We are supporting campaigns nationally and locally to ensure autism stays firmly near the top of everyone's agenda. It is important that we all take the opportunity of not just demonstrating the impact of investing in services but the impact of *not* investing in services. The autism helpline can help you to have a good understanding of your rights. The NAS has also produced a campaigning toolkit to help you campaign at a local level against cuts.

You can download the toolkit from our website <http://www.autism.org.uk/news-and-events/news-from-the-nas/nas-launches-new-guide-to-challenging-cuts-to-local-services.aspx> or e-mail [campaign@nas.org.uk](mailto:campaign@nas.org.uk)

To support our campaigning work it is a good idea to become a member of the NAS. The more support we have, the more authoritative our voice will be.

### In the NAS survey on diagnosis, parents said that they felt they lacked support after diagnosis and were often left to fend for themselves on a daily basis. What is the NAS doing to support parents of newly diagnosed children?

Let's get back to basics here - the fundamental problem is that there are too few specialist diagnostic services and as a result there is no 'need' to provide post diagnostic support. And for those who do go 'out of county' to access a diagnosis there will be no guarantee that this will be recognised by their home authority.

This has to be put right. The National Institute of Health and Clinical Excellence (NICE) has recently published a draft guideline on diagnosing autism in children and young people. The final guideline will be published later this year. This should help improve consistency in diagnosis across the country and improve the experience for children and families. As a result of our campaigning, NICE is also developing a guideline on support and interventions for children with autism, which is expected to be published in the next few years.

We all know that there is plenty of evidence to support the impact of early intervention on the outcomes for children and young people and this must surely start with early diagnosis. AuKids magazine really does fill a gap here. For many parents not knowing where to turn, the articles and case studies from professionals and parents provide a valuable source of advice.

The NAS also provides a number of resources - see [right](#). ➔

### The survey also indicated that there is widespread ignorance on autism in the education sector, with children in a mainstream setting suffering as a result. How can we educate mainstream teachers on autism?

There are some notable pockets of good practice but unfortunately the landscape is patchy and varied. There is plenty of evidence to suggest that young people on the spectrum do not get the support they deserve in mainstream education. This is evidenced by the horrendous bullying and exclusion statistics that blight the lives of many families.

Our Make School Make Sense campaign raised the profile of this issue but there is still much to be done. The SEN Green Paper sets out the Government's proposals for reforming the SEN system and training is a key theme. Given that there are 88,000 school aged children with an autism spectrum condition in England and that the vast majority of them are in mainstream schools, every school should be ready to support a child with autism.

Each school should be able to access specialist expertise to help them. There is a separate information section on our website for professionals, which includes training programmes available from the NAS which I would encourage teachers to consider. The NAS Autism Accreditation scheme provides a 'kitemark' of good practice and I would encourage schools to take part in the scheme if they are serious about providing support to young people with an ASD (Autism Spectrum Disorder).

### What do you think of the Statementing process as it stands?

I think we all agree that the current system is far from perfect, but it does give parents some statutory weight in their battle for appropriate support. The SEN Green Paper sets out a number of fundamental changes to the system, not least of which is a combined health, social care and education assessment. We see this as a positive move, but only if statutory enforcement is maintained. We are currently capturing views from parents and young people as part of our own consultation on the Green Paper and will be submitting these to the Department of Education to ensure that any new system better meets the needs of families affected by autism.

To stay up to date with the work we are doing on autism education, sign up to the NAS education update. See [nas-education-update.blogspot.com](http://nas-education-update.blogspot.com) for more information.

### There are huge inconsistencies in services available to parents of autistic kids throughout the UK. How can we strive to avoid a postcode lottery?

We recognise this - and many of the parents calling our helpline raise this as an important issue. A lot of the problem is down to the low levels of autism awareness and training amongst professionals who have a responsibility to support young people with an ASD.

Our 'You Need to Know' campaign highlighted the outrageous situation for children in the CAMHS system and called for a number of changes to support young people in the mental health system. As part of the campaign, we worked with a group of young people to draft a Charter for CAMHS services on what they could do to better meet the needs of children and young people with autism. The group recently launched the Charter and a film about making the Charter and we are asking local health

commissioners to sign up to it. See: [www.autism.org.uk/Get-involved/Campaign-for-change/Our-campaigns/You-Need-To-Know.aspx](http://www.autism.org.uk/Get-involved/Campaign-for-change/Our-campaigns/You-Need-To-Know.aspx) for more information.

We will continue to work at both a national and local level training of professionals in autism across the public sector.

### On holiday in Denmark, a reader said she was struck by the much greater level of autism awareness than you would find in the UK. How can we improve the situation?

Greater public awareness really is the Holy Grail for all of us. We would love to have the budget to run massive national media campaigns. Until we do, we actively try to generate coverage of the issues on the back of our campaigning and lobbying work along with the impact of our service delivery at a local level.

Our relationship with national politicians is good. We frequently come out in the top three when they are surveyed on which campaigning organisation is the most effective. Given the scale of some of the organisations, this is no mean feat. Our work in achieving the Autism Act (the first ever piece of disability-specific legislation) and the delivery of a national strategy for adults with autism is evidence that autism is embedded within the political agenda. However, there is much more to do and our You Need to Know campaign is evidence of this. We must never underestimate the impact that parents can have at a local level by speaking with one voice - please join us to add weight to our voice.

### Finally, what changes have you seen since in recent years that you have found encouraging?

There is much to be encouraged by but still much, much more to do! I am encouraged by the political response we have received to our campaigns over the last two or three years which have delivered tangible outcomes at a national level. I am encouraged by the more realistic and positive portrayal of autism in the media. I am encouraged by the interest shown by professionals in our conferences - attendance is growing every year, and I am encouraged by organisations' willingness to work collaboratively.

However, we still need to translate national policy to improve services at a local level, we still need to remove the stigma associated with autism and we still need to improve awareness and understanding so that families affected by autism are free to live the life they choose. I for one will continue to work hard to ensure that the NAS does its bit in trying to achieve this.

## LINKS

### SOS: Save Our Services

A toolkit on fighting cuts at a local level: [www.autism.org.uk/en-gb/news-and-events/news-archive/1-january/nas-launches-new-guide-to-challenging-cuts-to-local-services.aspx](http://www.autism.org.uk/en-gb/news-and-events/news-archive/1-january/nas-launches-new-guide-to-challenging-cuts-to-local-services.aspx)

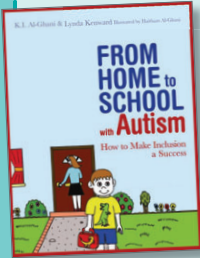
Joining The National Autistic Society [www.autism.org.uk/en-gb/shop/nas-membership.aspx](http://www.autism.org.uk/en-gb/shop/nas-membership.aspx)

Join Our Campaigner Email List [e-activist.com/ea-campaign/clientcampaign.do?ea.client.id=10&ea.campaign.id=95](mailto:e-activist.com/ea-campaign/clientcampaign.do?ea.client.id=10&ea.campaign.id=95) to be kept up to date on our campaigning work

NAS Education Update [nas-education-update.blogspot.com](http://nas-education-update.blogspot.com)

# New Books

The following publications are hot off the press from Jessica Kingsley Publishers.



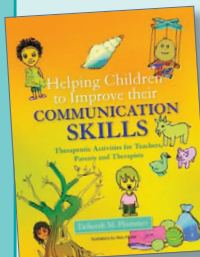
## From Home to School with Autism - How to Make Inclusion a Success

By K.I. Al-Ghani and Lynda Kenward

Illustrated by Haitham Al-Ghani  
£19.99 • ISBN 9781849051699

Beginning school is a challenging time for most young children. For those with an Autistic Spectrum Disorder (ASD) the significant change this entails can be overwhelming, and everyone involved will be in need of guidance to make the transition as smooth and as stress-free as possible.

This positive and practical book arms schools with a wealth of essential information, easy-to-implement strategies and photocopiable resources that will help to make early school days an enjoyable experience for young children on the spectrum.

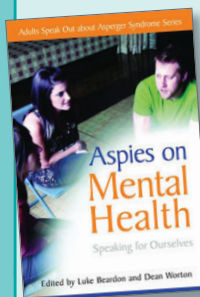


## Helping Children to Improve their Communication Skills - Therapeutic Activities for Teachers, Parents and Therapists

By Deborah M. Plummer

Illustrated by Alice Harper  
£18.99 • ISBN 9781843109594

This creative book is full of fun and imaginative ideas to help children aged four to 11 with a speech or language delay or disorder to develop their communication skills. It is packed with activities and games specifically tailored to help develop skills such as articulation, vocabulary development, breath control, conversation skills and non-verbal communication. Tips for personalising and shaping the activities are also provided. A comprehensive theory section supports the ideas presented, and practical advice on working with groups and individuals and in different settings is also given.



## Aspies on Mental Health - Speaking for Ourselves

By Deborah M. Plummer

Edited by Luke Beardon and Dean Worton  
£14.99 • ISBN 9781849051521

People with Asperger Syndrome (AS) can be particularly at risk of developing mental health difficulties such as anxiety and depression. Here, adults with Asperger Syndrome speak out about their own experiences of mental health issues, offering sound advice for other Aspies and providing valuable insights for family, friends and also for mental health professionals.

# Reviews



## BOOK The Daily Journal of Arabella Crumblestone

By Sharon King

Available from [www.sharonkingbooks.co.uk](http://www.sharonkingbooks.co.uk)  
£5 plus £1.50 p&p - £1 of the cover price is donated to the National Autistic Society

The Daily Journal of Arabella Crumblestone is a charming tale about what happens when a fairy is taken from her home (a stone wall) when she is found by two children on holiday. The well-meaning children befriend Arabella and through her diary we witness their touching attempts to understand her. One of the human children, George, has autism, and through the fairy's eyes we see him afresh - not as society sees him, but as a warm human spirit. Throughout the story, there's a sense of natural order, depicted in the beauty of the

passing winter season. Values such as caring, constancy, loyalty and love are all important elements of this gentle story.

The fact that the children in the book are based on the author's own family lends this little book a touching context, and daughter Rose (who appears in the tale as Faith) is the 12 year old artist behind the story's lovely little sketches (See page 4).

Little girls aged about nine to 12 will enjoy Arabella's adventures.

## Competition

We have copies of the book to give away to five lucky readers. Just answer this question.

### Real-life artist Rose King is depicted as which character in the Daily Journal of Arabella Crumblestone?

Send your answers to [auidsmag@gmail.com](mailto:auidsmag@gmail.com) or to AuKids Ltd, PO Box 259, Cheadle, Cheshire, SK8 9BE no later than June 30. The first five correct respondents will be notified by post.



## BOOK Inclusion in the Primary Classroom - Support Materials for Children with Autistic Spectrum Disorders

By Joy Beaney and Penny Kershaw

Published by the NAS  
2007 • £8.99 • NAS code 495  
ISBN 9781899280957

We like the opening statement of this slim volume. It says 'We are often asked 'Why should I do all this for ONE child in my class?'' We believe that the ideas and strategies we suggest will benefit *all* the children in the class.'

So say authors Joy Beaney and Penny Kershaw, who wrote this excellent guide to supporting autistic pupils in a mainstream setting,

published by the National Autistic Society.

Both authors are teachers and former SENCOs with bags of experience of working with autism in mainstream settings. The guide takes the reader in detail through common traits and difficulties and then moves on to give simple, practical advice on how to adapt the curriculum and the learning environment to support an autistic pupil. It includes a guide to using visuals with examples of visual timetables, talks about unstructured times and promoting positive behaviour and has a great guide to making your own Social Stories™.

As well as a useful further reading list at the end, it also incorporates forms to fill in, so that teachers can start putting what they've learnt into practice immediately. A super resource for teachers who may be new to working with a child who has autism or Asperger's.



## CD-ROM Playing with Sounds and Letters

From Yellow Door's Come Alive Phonics range  
£60 • Available direct from [www.yellow-door.net](http://www.yellow-door.net)

I'm not going to fib, this award-winning CD-ROM comes with the sort of price tag that will make you raise an eyebrow or two. But it's worth a mention because I've never seen quite such an engaging way of learning the alphabet designed for special needs kids. Each letter comes with its own song and little theme. So for 'a' it's an acrobat moving around a circus ring that's in the shape of the letter, and for 'b' it's a boat moving down a canal in the shape of the letter, you get the idea.

The phonetic sound of the letter is repeated as part of that letter's song with constant

reinforcement, so it's great speech and language therapy, too.

Whilst the child is following the action, they're also following the path of the letter. A highly interactive element allows them to trace the letter whilst moving another shape along it.

This is a lovely resource, imaginatively designed for learning through play and highly recommended. It really engaged my son Alec, who has severe learning difficulties as well as autism. Bobby, who is high-functioning and in a mainstream school, enjoyed practising the letters too, so it works on every level. Have a look at the demo at [www.yellow-door.net/come-alive-phonics/interactive-cd-rom](http://www.yellow-door.net/come-alive-phonics/interactive-cd-rom)

Debby Elley

## Write Your Own Review!

Send in your reviews of a book or DVD to [auidsmag@gmail.com](mailto:auidsmag@gmail.com)  
You can also review items from your child's point of view - older children may like to write their own reviews. No more than 150 words, please.

## Not got much cash spare?

Cerebra is a UK charity for children with neurological conditions including autism. This fantastic charity operates a really great postal lending library with plenty of books on autism - you can borrow books and sensory toys with no postage costs to pay. Just look up [www.cerebra.org.uk](http://www.cerebra.org.uk)

# The Last Word



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

## When it Comes to the Crunch, We Like the Difference

Having said So Long, Farewell, Auf Wiedersehen, Goodbye to my diet, I was recently chomping my way through the new broken biscuits selection that our milkman had delivered. The development of doorstep deliveries has been universally welcomed by my family, who recognise that when it comes to my strengths, regular stock taking of the fridge most definitely doesn't feature.

Gavin was joining me in perusing the surprise contents of our broken biscuit box and we ended up bemoaning the narrow-mindedness of our society, one that maintains that only a biscuit which is a hundred per cent perfect will eventually make it into the packet.

"I mean look at me," said Gavin, impersonating a jammy dodger. It's difficult to know how to personify a biscuit, but humanising random objects is something that he does rather well. He once had me on the verge of tears by adopting the wretched manner of a neglected wooden cuckoo that had been locked inside our hall clock for several months (on account of it being so ruddy annoying). By the end of his pitiful soliloquy, it was allowed to warble from the landing until well into the night.

Anyway, "Look at me," says the talking biscuit. "What's wrong with me? Why didn't I make it into the packet? All my friends did..." (sad face).

There is nothing wrong with this biscuit at all, I can testify, as I scoff it in a single gulp. The factory machine that stuck it together may have been having a bit of an off day, maybe it broke up with its girlfriend the night before or something. In any case, it wasn't really looking at what it was doing and the result was a slightly misaligned biscuit. Nothing drastic, just a bit skewed. Other biscuits had met a similar fate, their delicious potential totally disregarded simply because on a very superficial level they didn't look quite right.

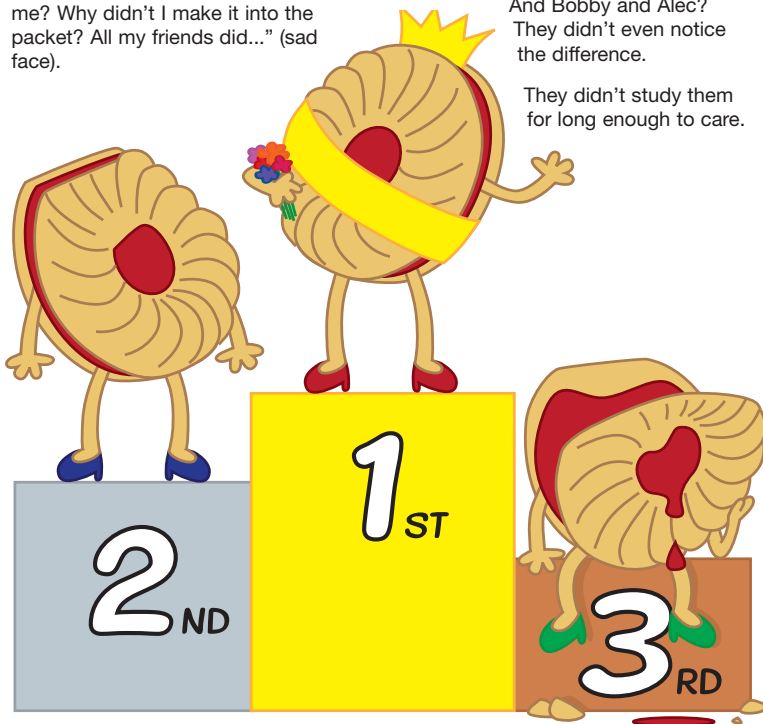
Thank goodness for the doorstep delivery service, we say, concluding that it's not only a good thing to buy these because they're a bit cheaper, but it also allows us to adopt the snooty high ground, hitting back at a society that reveres perfection and can't see the good in anything slightly different.

Of course, that made us think of autism. If biscuits that are a bit different are frowned upon, what chance have human beings got?

Luckily, there's people like us, who not only like these broken biscuits just the way they are, but actually prefer them, enjoying their unpredictability and celebrating their quirkiness with an enthusiasm that may well, to the outsider, suggest a rather lame social life.

And Bobby and Alec?  
They didn't even notice  
the difference.

They didn't study them  
for long enough to care.





**Thomas Cason**  
aged 3

**Diagnosis:** Autism.

**My family:** Mummy, Daddy, Big Sis Eleanor and Maisie the dog.

**School:** Loddon Nursery School, Norwich.

**Best habits:** Always happy and laughing.

**Worst habits:** Wanting everything NOW!!!! Breaking computers and Wii consoles.

**I love:** My big sister Eleanor, dancing, our trampoline, my train set and being outside.

**I hate:** Hot food, not getting my own way.

**Ambition:** To be able to get my point across.



## Celebrity Spotlight



**Fraser Burrows**  
aged 4

**Diagnosis:** Autism.

**School:** St John's Pre-school Playgroup, Carlton, Nottingham.

**I love:** Chocolate biscuits, jumping, big hugs, having fun at playschool, In The Night Garden and Mr Tumble and going to the park.

**I hate:** Getting my hands dirty.

**My personality:** Jumpy, funny and cheeky but a bit stubborn.

**Ambition:** To ride on the Ninky Nonk with the Tombliboos (like you do - Ed.)



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](mailto:aukidsmag@gmail.com)

# PS

### An OASIS for parents

If you're looking for advice on schooling, Statementing or special needs in general OASIS is a free and impartial SEN information service. It has free downloadable information sheets, a helpline and email enquiry service. There's also a specialist ASD advisor who can give talks to parent support groups within a reasonable travelling distance of Hampshire. OASIS is supported by the Cambian Group which runs a range of specialist independent residential schools in the Hampshire and Dorset regions. Look up [www.oasisis.co.uk](http://www.oasisis.co.uk) for details.

### KEEP IN TOUCH

At [www.special-needs-software.co.uk](http://www.special-needs-software.co.uk) you can find simple games designed for touch screen computers, all for free or £1 to download! Lovely!

### Best route for transport fans!

At [www.dingding.org.uk](http://www.dingding.org.uk) you can learn about buses, trains and trams using games and cartoons. Ideal for all our little transport fans! The site is safe and free to use.

### To Boldly Go Where No Website Has Gone Before...

A new website aimed at parents of children with disabilities has been launched for the West Sussex area. **Reach Out** [www.reachoutwestsussex.org.uk](http://www.reachoutwestsussex.org.uk) is a fantastic resource aimed at helping parents to find the best information, advice and places to go in the region.

### Tactile Tassels

'Albi loves to play with people's hair. As an alternative I got him old curtain tassels which work nicely.' Thanks to Netbuddy for this! [www.netbuddy.org.uk](http://www.netbuddy.org.uk)

### Sorting the Stress

'My son Jacob is seven years old and has ASD. He has very high anxiety levels and worries about lots of things. Every night, after story, we do 'worry time'. We talk about about all my son's worries that he has put in his worry box (in his head) throughout the day. We also have a 'deep worry box' which we open up, too. It's a fab way of helping him deal with his anxieties with lots of reassurance and cuddles from his mum.' Thanks to Netbuddy for this! [www.netbuddy.org.uk](http://www.netbuddy.org.uk)

Awww, fab parent!

