

# Aukids®

Issue 24  
Summer 2014

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Positive Parenting for Children with Autism Spectrum Conditions



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# Letter from the Editors



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For more information on any of our services please visit [www.cygnethealth.co.uk](http://www.cygnethealth.co.uk) or call Cygnet Central: 0845 070 4170

For more information contact Saskia Little, Administrator  
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**TICKLED PINK:** Co-Editor Tori Houghton (2<sup>nd</sup> from left), Co-Editor Debby Elley (far right), Breanne Black (4<sup>th</sup> from right) and the team at Autism Support Gibraltar.

Photography courtesy of The Gibraltar Chronicle

## Welcome to our summer issue!

Well, it's been busy! In May, it was our much anticipated (by us, anyway) trip to Gibraltar. Tori, Debby and our Ask the Expert panellist, occupational therapist Breanne Black, addressed the island's first autism conference aimed at parents. As a result, we now have some new Gibraltarian readers, so welcome to you guys!

In terms of autism provision, Gibraltar, which is British, is quite far behind the UK. We have access to so much more regular support here, not to mention constant opportunities to hear top international speakers and hop on board useful seminars. We really are lucky, let's not forget it.

The group of parents who hosted us in Gibraltar have formed a new charity to plug the gap in provision over there, called Autism Support Gibraltar. Together with occupational therapist Janine Gaduzo, who invited us out there, they have built something really special. All it took was passion and enthusiasm and hey presto, they'd organised themselves a conference. It's a great lesson in what can be achieved by just a small group of friends wanting to make a difference.

If you've formed a new support group or want to give a mention to one, don't forget that's what our Facebook site is for!

**COMPETITION WINNERS FROM ISSUE 23**

Melinda Balatoni, Batsheva Kaye, Nicola Naylor, Paula McClinton, Nic Hadley, Judy Newton, Mandy Potts, Lee Guard and Rejharne Nesfield. *Aiden the teddy was hiding at the top of Page 10 in the little boy's hand.*

Thanks to our hosts we managed to squeeze in a tour of Gibraltar before the conference, and met their famous Barbary Macaques. They're very cute but not always so friendly if you haven't got food on you, hence this pic of Tori trying to charm her way into this monkey's comfort zone (and failing completely).



In other news, Debby's blog has been renamed Spectrumite Mum (check it out via our website) and we've added some new slogans to our T-shirt range.

Cineworld cinema at Grand Central Stockport has taken a particular shine to AuKids - so much so that they've displayed this poster for us outside their autism friendly screenings. Thanks Cineworld!



We look forward to updating you in the autumn.

*Tori & Debby*

e-mail: [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com)

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**EDITORS:**  
Tori Houghton and Debby Elley

**PHOTOGRAPHY:**  
Front cover photo taken by David Laslett at [www.manchesterphoto.com](http://www.manchesterphoto.com)  
m: 07918 155362

**PRINTING:**  
R and P Printers, Dukinfield

**GRAPHIC DESIGN:**  
 **periscopestudios**  
[www.periscopestudios.co.uk](http://www.periscopestudios.co.uk)

AuKids is published by AuKids Limited, PO Box 259, Cheadle, Cheshire SK8 9BE, company number 7413180.

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## Playtime

I love to sit and watch Josh and Rosie play,  
It's something that I love to do every single day.  
Although it's unconventional and in their own way -  
I love to sit and watch Josh and Rosie play.  
I tell Josh to throw Rosie the ball,  
So he drops it right by her foot, where she is lying in the hall...  
"That's not quite what I meant," I say with a smile;  
I think for him to do it conventionally will take quite a while.  
But why does it matter how they choose to play?  
Who is to say what makes the right way?  
So for now I'll just sit back and enjoy  
My son and his dog playing with their toy.

By reader Gemma Wilkin

Josh and his dog Rosie



## Celebrity SPOTLIGHT



Jaxon Cooper

**Age:** 6

**Diagnosis:** Autism, Epilepsy, Non-Verbal

**Where I live:** Trowbridge in Wiltshire

**Jaxon's mum says:** He may not be speaking yet but using PECS with his gorgeous smile and happy nature gets him a long way. He is very affectionate and loves a cuddle. Every now and then when he's a little sad he comes to you for an emotional recharge and then he's off again with a glint in his eye and a grin to melt hearts.

He's a star because he has just progressed to 'I Hear' using PECS and he is sitting and focusing for longer periods at school, well done Jaxon!

He loves going on car journeys, his iPad, crisps and watching cleaning product adverts over and over! He dislikes losing the TV remote, and trying new food!

Send your celebrity details to [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com)

**I like:** Going on car journeys.  
**I dislike:** Trying new food!

## ADMIRING AUTISM

Admiring Autism is a photographic exploration into the world of autism, the brainchild of Chester-based photographer Sara Jane Dunn, whose son Frank, aged two, has autism.

This year, Sara will live for two days with 15 families who have children with autism, photographing them as they go about their daily lives. Admiring Autism is a not-for-profit, social documentary campaign, which hopes to raise awareness about autism through photography.

You can follow Sara's project

on Admiring Autism's Facebook page or look up [www.admiringautism.co.uk](http://www.admiringautism.co.uk) Sara is currently seeking a grant from the Arts Council and donations via Crowdfunding sites to continue and expand her work.

We loved this photo of Sara's son Frank and his cousin Mischa sharing a moment of joy.

Sara says: "I asked Mischa, can you tell Frank is a little different from other children his age?"

Six year-old Mischa responded: "Well, yes. He likes to spin a lot and scrunches up his cute face to look at the wheels and looks like he's concentrating a lot...he looks very serious, ha ha. Other children would hold it further away and maybe not spin as much. But I love him because he is special, he is different, he is my cousin. He makes me laugh so much."



Frank and Mischa

## Cover Star

Rayaan is 4 (nearly 5!) and lives in Longsight, Manchester.

He is into cars and transport. His favourite cars are Audis and Disney's Lightning McQueen.

He loves Fireman Sam and is good with

technology - he knows how to work a mobile phone and various tablets including iPad. He enjoys the outdoors and McDonald's.

His favourite foods are fish fingers and cheese sandwiches.



Rayaan



Dear Aukids,

I am a full time teacher who recently was on a conference which you attended. I craft part-time and create items to raise awareness of autism. These include mobile phone cases from £12, iPad cases from

£20, iPod cases from £12 and a range of bags, brushes, hair accessories and other gifts.

I raise funds for my local autism support group, Love Autism in the North West, based in Wigan, and am in the process of setting up charity registration with the National Autistic Society. I don't yet have a website but you can find my work on Facebook at Unique Pieces by Stacey. You can find the support group at [www.loveautism.org.uk/northwest.php](http://www.loveautism.org.uk/northwest.php) - Twitter @LoveAutismNW - Facebook LoveAutism.

All the best, Stacey Halliday

Phone case





# Reviews & Prizes



## The Disappointment Dragon: Helping Children Including Those with Asperger Syndrome to Cope with Disappointment

By K.I. Al Ghani • Published by Jessica Kingsley  
RRP £12.99 • ISBN 99781849054324 (Hardcover)

This is a great therapeutic story book which cleverly conceptualises the feeling of disappointment as a dragon. The 'disappointment dragon' feeds off the negative emotions expressed by a child when disappointed. The stronger the emotions, the more 'fuel' the dragon has to travel to the Valley of Despair.

Written by a Specialist Advisory Teacher for autism, with more than 35 years' experience in education, the story is based around a school classroom and its pupils, some of whom have to deal with disappointing news.

Aimed at any child who may be struggling to deal with their emotions when things don't always go to plan, the visual concept would particularly appeal to children with autism, helping them to understand the feeling of disappointment.

This book serves as an excellent discussion point about coping strategies and 'armour' that can help the children to fight off the disappointment dragon, invite the 'Dragon of Hope' and travel to the 'Mountain of Happiness'. At the end of the story, there are notes and discussion points with additional strategies to try.

I would definitely recommend this book to parents and teachers (both special needs and mainstream) to read with their children and to implement the strategies.

**Tori Houghton**

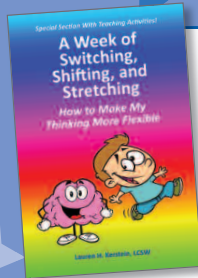
Co-editor AuKids, Speech and Language Therapist

**WIN  
A COPY!**

We have copies of *The Disappointment Dragon* to give away to THREE lucky readers. **Simply find the dragon hidden inside this copy of AuKids magazine.** Then send your answer to [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com) with 'dragon' in the subject header. You can also send your answer to us at AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE. Closing date August 31<sup>st</sup> 2014. If you don't win, you may have to buy it to cope with the disappointment!



Find the dragon →



## A Week of Switching, Shifting, and Stretching: How to Make My Thinking More Flexible

By Lauren Kerstein  
Published by AAPC  
RRP £13.95  
ISBN 9781937473891

This is a great little book for kids on the spectrum and their parents. It uses Cognitive Behaviour Therapy to help a child become more flexible in their thinking. Each colourful cartoon illustrates a scenario at home or at school. The central character, who talks about his experiences in the first person to help readers identify with him, shares his rigid thoughts with the reader and how these lead to bad feelings when things don't go

as planned. In each case, he repeats that he needs to find his 'brain-poline' – a brain trampoline in rainbow colours where he can jump from black and white into the rainbow in between. After being mentally flexible, he solves his own problems by finding suitable alternatives. Ideal for ages seven and up, the author has made cognitive behaviour therapy into a really fun little book that's easy to get through, reinforces the same messages repeatedly and is highly positive. There's a great little section at the end for parents, with further exercises and games to encourage flexible thought.

My ten year old son Bobby read it and said 'I really loved it! I loved all the colours and the rainbows. Now all I have to do is do what it says!'

**Debbie Elley**  
Co-editor



## The Asperkid's Launch Pad: Home Design to Empower Everyday Superheroes

By Jennifer Cook O'Toole  
Published by Jessica Kingsley  
RRP £12.99  
ISBN 9781849059312

Jennifer Cook O'Toole is a mother of three young children with Asperger's. Jennifer herself was diagnosed with Asperger Syndrome in childhood and is the founder of Asperkids LLC, a multi-media social education company.

The book is a bright and simple guide to making your home a refuge and safe spot for your child where they can hone their concentration skills, take pride in their work and build independence.

In the chapter 'The Place' the reader is given some excellent tips and tricks for

fostering independence. Jennifer draws from her own experiences and those of her children to break down every day routines and chores like pouring a drink or tidying up.

Fun photographs show ideas for inspiring your child's creativity and thirst for learning. Bath time becomes a super place for science experiments. The garden can easily and economically be transformed into a space to develop confidence in movement and motor planning. A 'Thinking Room' in your home may be a retreat purposefully stocked with books and objects that will inspire curiosity and conversation.

All in all this is an easy and quick read with some great advice about how to create a more organised and happier household for your 'Asperkid.'

**Melissa Carr**  
AuKids' reader panel



## Social Situation Stories: Tricky Times

By Alison Harris  
Published by Specialdirect.com  
RRP £16.95  
ISBN 9781906213602

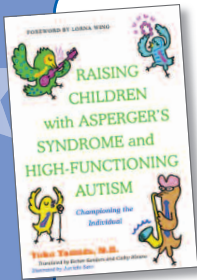
A while back we reviewed Social Situation Stories by the same author and it's still a book I'd highly recommend. This new version takes the same format but includes stories to explain tricky times that can be adapted to suit your own purposes. It's worth pointing out that these aren't Social Stories™ in the same sense as the 'official' ones that Carol Gray developed. They aren't quite the same format, which is why they're referred to as 'social situation stories' instead. They still explain situations calmly and clearly,

highlighting only the most important information and making tough times a little easier to understand for autistic children.

All sorts of school issues are covered, including what to do in sudden changes of routine such as supply teachers, forgotten lunchbox, someone new in class, moving schools and wet playtime. Home issues include the very hardest of situations – divorce, illness and death.

As in her previous book, Alison has really thought this through from a child's perspective, with plenty of common situations covered that will help parents and teachers to give a primary school child comfort and direction. I particularly like the advice boxes after each story, focusing on what a parent or teacher could do to support the child around the situation story itself.

**Debbie Elley**  
Co-editor



### Raising Children with Asperger's Syndrome and High-Functioning Autism: Championing the Individual

By Yuko Yoshida  
Published by Jessica Kingsley  
RRP £12.99  
ISBN 9781849053174

The author is a child psychiatrist in Japan, specialising in diagnosing and treating children and young people with autism spectrum and other developmental disorders. It is well written with an easy to read approach, definitely a 'sit with a cuppa' read as opposed to notebook and pen.

The book immediately gains credibility with the introductory forward by the late Lorna Wing, leading consultant for autism. (sadly Lorna recently died - eds).

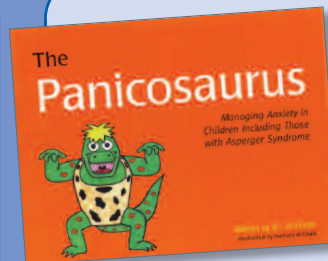
This is a useful read for anyone who is parenting a child with Asperger's/high-functioning ASC, whether they are in the early stages of diagnosis, or want an easy read that will inform them about a variety of problems that these children face. I would also

recommend it to professionals who are new to working with children who have a diagnosis of Asperger's or high functioning autism.

The book doesn't go into great detail about the issues that those with ASC or their parents encounter, but it does give a sound overview. I assume it's not the aim of the book to give lots of facts and in-depth heavy reading, as the way it is written ensures it is accessible to everybody. It is split into three chapters and gives enough advice and information to cover 'What is autism?' 'Parenting' and subjects such as picky eaters, communication approaches and some useful information around sensory issues.

It is easy to flick through to find a specific question from a parent, which could be the same question that has been puzzling you. Overall, a useful book for parents to use as a handbook - you may skim read parts initially, but keep it to hand as issues that aren't relevant at the time may well crop up in the future.

**Beccy Timbers**  
Speech and Language Therapist



### The Panicosaurus: Managing Anxiety in Children Including Those with Asperger

By K.I. Al Ghani  
Published by Jessica Kingsley  
RRP £12.99  
ISBN 9781849053563 (Hardcover)

Written by the same author who wrote The Disappointment Dragon reviewed by Tori, this book is again aimed at all youngsters, but is particularly good for those with an autism spectrum condition who have multiple anxieties.

This is an excellent tool for parents and teachers to help explain what happens

to our bodies when we feel anxious, with strategies to help the child alleviate anxiety.

It's an easy read using simple language and tells the story of a young girl called Mabel with ASC who has lots of anxieties. Her parents have used the character Panicosaurus, a naughty dinosaur who appears when she feels anxious, to help her understand how she's feeling. Smartosaurus, a good dinosaur, gives her strategies to help relieve the panic. There are also lovely colourful illustrations to accompany the story.

I really enjoyed reading this and would definitely use it with any child who is struggling with these issues. It also has some excellent ideas to use at home and in the classroom, to make the school environment a less scary place!

**Alison Walters**  
AuKids readers' panel



## a Magnetic Responsibility Chart!



New online marketplace RosyandBo.com feature gifts, products and toys for children with special needs and has a growing range of autism products.

By reshaping the distinction between ability and disability, bridging the gap between mainstream and special needs, RosyandBo.com sees the child and their family first and brings them products that embrace children's needs as individuals and great ideas to enhance the everyday lives of families.

We bring together all the things, everyday and out of the ordinary, that make family life with children of every kind - special or otherwise - easier and lovelier.

**Three lucky readers have the chance to win a Magnetic Responsibility Chart, worth £11.99, from RosyandBo.com.**

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To enter simply visit [www.RosyandBo.com](http://www.RosyandBo.com) and Sign In at the top of the home page, and from the dropdown menu 'How did you hear about us?' using the 'other' option, enter the code 'Aukids'.

Competition closes August 31<sup>st</sup>.

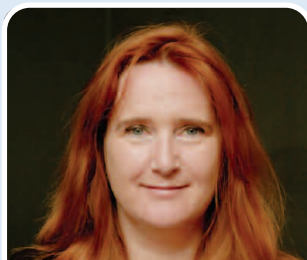




Photograph courtesy of Admiring Autism - [www.admiringautism.co.uk](http://www.admiringautism.co.uk)



## “ Why does my son spin things? ”



**Dr Jacqui Rodgers**

C.Psychol, AFBPsS

Senior Lecturer, Clinical Psychology, Newcastle University

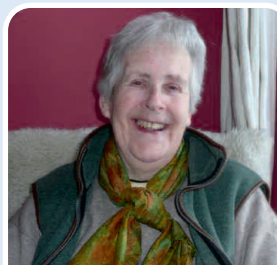
Have you ever spent time watching the flickering flames of a real fire or gazed at the ripples in a pool of water? How did it make you feel? Many people describe these experiences as very relaxing or calming, a way to tune out for a while and shut out the outside world.

Perhaps spinning provides similar sensations for people with Autism Spectrum Conditions (ASC)? Sometimes the world can seem a very busy and overwhelming place with so much going on and so many individual stimuli to attend to. This may be especially the case for people with ASC who are often exquisitely able to notice very small details in their environment and are therefore processing even more information than those of us without ASC.

When these feelings of being bombarded with information occur, perhaps focusing on something predictable and soothing, like a spinning wheel, provides the respite needed in a busy, booming world.

We know that people with ASC sometimes find uncertain situations difficult to deal with. Imagine how uncertain the world may seem if you are really good at noticing the tiny details of your environment, picking up on the tiny changes that pass most of us by. One thing you might do in this situation is to engage in an activity that provides certainty and predictability in an uncertain world – spinning may do just that.

It is likely however that there is no one single explanation for why people with ASC seem to enjoy spinning objects, the reasons will differ across individuals and may even differ within individuals across different situations. On occasion, engaging in spinning may be a method of managing high arousal or anxiety by instilling a sense of calm. On other occasions it may be a way of self-stimulating to avoid feelings of under-arousal or boredom. Spending some time observing when spinning occurs, what precedes it and what happens afterwards will provide some insight on an individual level.



**Phoebe Caldwell**

Honorary Doctorate of Science (DSc)

Phoebe Caldwell is an expert practitioner in Intensive Interaction and trains professionals, therapists, managers, practitioners, parents and carers in the approach. Her latest book is *The Anger Box, Sensory Turmoil and Pain in Autism*, published by Pavilion.

If in doubt about behaviours, ask the experts, the people with autism. Read what they are saying about the reasons they behave in certain ways.

If we do this, the first thing we realise about children with autism is that their experience of the world we share is completely different from those of us who are not on the spectrum. One of the features of this is that the brain cannot filter out incoming signals that are important from what is not important. So the brain is behaving like a runaway kaleidoscope, where the pattern never settles. Children (and adults) on the spectrum spend their whole lives trying to sort out the pattern of what is happening to them (Therese Jolliffe).

There seem to be a number of reasons that trigger repetitive behaviours such as spinning objects. Temple Grandin says she used to spin coins in order to cut out the sensory overload (Film 'A is for Autism'). On the other hand, Sian Barron says he turned the light switches on and off in order to know what he was doing. Tito flaps his hands and gives us a third alternative:

'I am calming myself. My senses are so disconnected, I lose my body. So I flap. If I don't do this, I feel scattered and anxious. I hardly realised

I had a body...I needed constant movement to be aware that I am alive and my name is Tito.' (Tito Mukhopadhyay, as seen on *60 Minutes* and *YouTube* (Mabry)). Tito is telling us he needs the sensory input he is creating by flapping, in order to know who he is.

All of these people are telling us about the search for coherence in the face of sensory overload, either by trying to cut out some of the input, or by focusing on a signal that is easy to process, because when they do it they know what they are doing.

It is very important not to try and stop them doing repetitive behaviours because if we do, we expose them to a situation where the brain simply crashes because it is unable to deal with the amount of data it is being fed. The child is now in danger of meltdown, which is painful and frightening. In order to make contact with them we need to join in with what they are doing. In this way we can transfer their attention from solitary self-stimulation to a shared activity. This approach is known as Intensive Interaction and basically uses a child's body language to communicate with them.

At the same time we need to take a careful look at what it is in their sensory environment that is overloading them and address these problems. It may be hypersensitivity to sound (particularly overlapping speech), intense light, pattern or certain colours, light touch, smell and taste, balance problems, or under-sensitivity from the joints and muscles. It could be emotional overload – the child reacts badly to praise or emotional warmth – or the hormonal difficulties experienced in puberty.

Remember, the brain works more effectively in a low-stimulus environment where there is not so much to sort out.



**Breanne Black**

BSc (Hons)

Specialist Paediatric Occupational Therapist

Cool For Kids Occupational Therapy  
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Repetitious behaviour or repetitive motor action is very common in people with autism.

It's often called 'perseveration' and is described in the diagnostic criteria for Autistic Spectrum Conditions. Examples of repetitive behaviours include spinning objects, flicking objects, hand and finger flapping.

Repetitive behaviours range from inflexible interests to self harming actions such as head banging.

Some children's repetitive actions are constant, whilst others only 'perseverate' when stressed, anxious or upset.

From an Occupational Therapist's viewpoint, we usually use approaches to help sensory integration. People can use repetitive behaviours to help them self-calm when they're feeling excitement, anxiety or frustration. So it's important to work out the purpose of the behaviour as far as he's concerned. Think about these questions:

1. When does this behaviour occur?
2. How often does it occur?
3. At what point does it stop?
4. What positively reinforces this behaviour e.g. It helps him feel calm?
5. Is it harmful to himself or others?

When you've identified the possible reason for the repetitive behaviour, you decide whether you're happy for it to remain. You may want to replace it with alternative sensory strategies that can help him to stay calm and self regulate.

**Alternative sensory strategies:**

The following are all strategies that occupational therapists will use to help a child remain calm but alert and focused:

- Jumping on the spot, jumping in different directions, running, skipping, if possible the use of

a mini trampoline.

- Obstacle course activities which use handstands, wheelbarrow walks, rolling, rocking, swaying and small amounts of spinning.
- Swings, a balance beam or seesaw.
- Vestibular games such as the 'washing machine': hold hands with outstretched arms, lean backwards and spin around like a washing machine.
- Rolling like a log, arms above head: encourage the child to grasp a small ball between their knees at the same time.
- Jumping side to side over a skipping rope (if they can)
- Bouncing on a gym ball
- Marching on the spot
- Jogging and running

**Calming strategies include:**

- Rocking
- Row Row Your Boat games
- Deep pressure / massage
- Use of bespoke chewy items
- Use of crunchy food
- Drinking through a straw
- Activities which involve push, pull, lift and stretch.
- Use of weighted items, such as lap pads, back packs.
- Discrete strategies such as sitting on your hands.
- Hand squeezes and wall pushes.
- Use of fidget toys which offer stretch and resistance
- Application of deep steady touch pressure by placing a heavy hand on the child's shoulders or allowing the child to have a fluffy toy they can hug tightly.
- Wrapping the child tightly in a blanket can also have a calming effect. This can be done as a game e.g. making the child into a 'hot dog'.
- Have the child lie on their back and encourage them to copy movements such as angels in the snow/sand. You can also stand opposite the child and ask them to copy your arm and leg movements, this should be done slowly.
- Encourage the child to listen to quiet or environmental sound music.
- Have the child rock slowly whilst listening to music or a story.

These are just a few examples of strategies which can be introduced in order to replace a repetitive behaviour which may have a sensory base.

The most important considerations are whether this behaviour is harmful to themselves or others, whether it's impacting upon their ability to function or whether it's just being used in order to help him cope with sensory or other environmental challenges. If it doesn't interfere with functioning and isn't harmful, do we really need to change or replace it?



**Tim Tuff**

Autism advocate, AuKids researcher and speaker

For me, there are two types of spinning. When I spin myself round, I'm unhappy. When I spin something else, I'm happy. This isn't the same for everyone. When I spin myself it's when I either feel very stressed or I feel like I've failed at something. It's a feeling I can't escape, like being in a tunnel. It feels like I can't move and to spin means that I've got room to move - it physically shifts me out of an emotional trap. It is as if my brain has got stuck on pause and the spinning moves it on. My 'bad' thought is always on my left hand side, so if I spin in the other direction I can knock it out.

As much as I've spun it out, it's still there until I can communicate

it. With the AuKids team, we found that if I draw the upsetting image and then throw it away, it helps. Debby and Tori also gave me a mood diary and I monitor my moods with stickers each day (plus little notes on what caused them). This helps me to get perspective (I can see a bad feeling only lasted part of the day) and the feelings don't build until they take over. It means someone else can also see when bad feelings are starting to build.

I know someone with autism who draws a picture of her bad thoughts and sticks it onto a ball. She then hits the ball against a wall so many times that she destroys the image. And because she's focused so much on drawing it, it really feels forgotten.

Happy spinning is totally different. For me it's because I like something and I want to have it constantly in my head. The spinning action helps me to keep the happy thought going, it creates a 'loop' in my brain. Focusing on something I like stops anything unpleasant getting into my head. All people have distractions when they don't like doing something. It's my way of 'being away with the fairies' as neurotypical people would say!

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



# DRY AND MIGHTY



Toilet training children with autism generally gets a bad press. Does it deserve it? I know of a number of children with autism who have been successfully toilet trained with no more effort than it takes to toilet train a child without autism. But I receive a good number of referrals for autistic children who are struggling with their toilet training, so here are some of the most common questions I get asked.

By Anna Turner, Paediatric Continence Advisor

## Q Can I train my child to use the potty before he can speak?

**A** Yes! Finding ways of communicating what you want your child to do is the key. You may need visual support like pictures, Social Stories™, even demonstrating! Motivation can be tricky - social motivation to be a 'big boy or girl' often has no impact at all. Some parents pin pictures of motivating interests in the bathroom, which can help. So use rewards based on special interests, rather than social reasons, to encourage them.

The child also needs a system to tell you that they want the toilet. This can be symbols, a sign, even a button they can press on the toilet door (see resources).

From my experience, patience and perseverance usually eventually pay off.

## Q How do I go about potty training my autistic son?

**A** A few hints on where to start:

### • Change the nappy in the toilet area...

...standing up if possible. This gives your child more opportunity to become involved in the process of toileting.

### • Get them comfy on the toilet

It is so difficult to relax enough to empty your bladder and bowel if you are worried about falling down the toilet, or your poo is going to hurt. Potty chairs can make the child feel more comfortable. Toilet seat inserts as well as steps can also be useful (see resources).

### • Be aware of sensory issues

We know that children with autism can have sensory issues to do with the noise of flushing toilets. In Phoebe Caldwell's book *The Anger Box*, she says 'A child who cannot bear the noise of a toilet flushing but loves horses, is reconciled to the sound when her mother pastes a large picture of a horse's head on the cistern'.

### • Get them aware of what their body is telling them

Work on their understanding of the concepts of wet and dry in general. Then help your child to spot the difference between wet and dry nappies/pull-ups/pants.

### • Get into a timed routine

Recognising the need to go to the toilet can take a while. Timed toileting is the best place to start. If you always take them at a certain time, you can prevent moments of tension when you are asking the child to stop a favourite activity.

### • Be aware of their routine

It may sound blatantly obvious, but if you toilet your child when he is more likely to wee or poo, then you stand a better chance of success - so make a chart. Put some good quality kitchen roll into the nappy and check it every hour to mark the time.

## Q How do I move on from promoted, scheduled toileting to my little boy asking to go?

**A** This can take quite a while to develop. Help your child by telling them how you know that they need a wee

or a poo, e.g. "When you do your 'wee dance' it means your wees are ready to go in the toilet," or "When you crouch behind the settee like that, it usually means your poo wants to go in the toilet, let's go and try". Making up a story about the poos 'going to the poo party in the sewers' has helped a few children.

Also ask them questions about whether they get a feeling in their tummy before they need a poo.

As a general rule, if the child is mostly dry with prompted toileting, the sensation of being wet or soiled feels different to usual, rather than at the start of the process where it is an everyday sensation.



## Q When I tried my three year old son without a nappy he did FIFTEEN wees in an hour and never seemed to notice

**until it was coming out of him. Is it a physical problem? Or does the autism always account for this?**

**A** Usually the bladder is fairly mature by the age of five - if your 3 year-old is weeing so frequently, it may be that it is just too soon to try.

Other causes of such frequent weeing could be:

- Drinking a lot. Between 6 and 8 drinks spread evenly throughout

## RESOURCES

• *The Potty Journey* by Judith Coucouvanais (AAPC publishing).  
*Suzie's Toilet Time* - by Charlotte Olson. From [www.suziebooks.co.uk](http://www.suziebooks.co.uk)

• *It Hurts When I Poop! A Story for Children Who Are Scared to Use the Potty* by Howard J. Bennett, Magination Press, (American Psychological Association)

• The Big Point button, £9 each. Record a short message on it. From Inclusive Technology, [www.inclusive.co.uk](http://www.inclusive.co.uk)

• BabyBjörn Toilet Trainer seat (adjustable) from [www.amazon.co.uk](http://www.amazon.co.uk)

• Amazon sells stickers from My Wee Friend for the toilet - watch the smiling star appear when the child uses the potty. Cheap, cheerful a range of designs - instant reward!



For boys, you can get target practice stickers for the toilet to help their aim, from [www.toiletmarksman.com](http://www.toiletmarksman.com) (also available from Amazon)

• If it doesn't freak out your little one, you can also get toilet stickers like this one from Amazon to make your loo less daunting: [www.amazon.co.uk/Smiley-Toilet-Bathroom-Sticker-Transfer/dp/B00ESK0JUO](http://www.amazon.co.uk/Smiley-Toilet-Bathroom-Sticker-Transfer/dp/B00ESK0JUO)



• Washable pants have padding and are great for that in-between stage. Buy them from P&S Healthcare on 0115 968 1188 or [www.pshealthcare.co.uk](http://www.pshealthcare.co.uk)

• Promocon is a charity that promotes continence. You can buy washable pants from them, and they also have a helpline - 0161 607 8219. Look up [www.promocon.co.uk](http://www.promocon.co.uk)

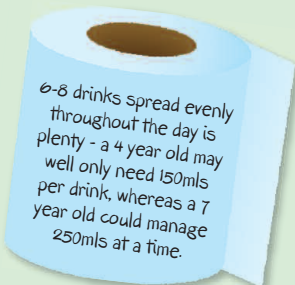


the day is plenty.

• Some drinks can make the bladder contract more than it usually would. It may be worth experimenting to see if certain drinks do cause his bladder to empty more frequently.

• There is medication that can help calm the bladder down, but it would be sensible to have a continence assessment before going down that route.

• There may be an underlying reason for the bladder emptying so frequently and this certainly should have settled down by the time the child is 5, so do ask your Health Visitor/School Nurse/Continence Nurse for support if you are worried.



A child who has poos that cause discomfort is less likely to start to poo on the toilet. Laxatives are often essential to break the cycle, but the dose needs to be right, so get professional advice! If you aren't

giving enough laxatives the soiling can get worse.

It's worth knowing also that children can start wetting again after having been dry, or have difficulty having a wee if they are constipated. Where holding down is concerned, each case is different and needs to be assessed by a healthcare professional.

**Q** My son gets extremely distressed when I put him on the loo for a poo. Why is this?

**A** There could be a number of reasons for this and the first thing to try would be a potty chair outside of the bathroom environment so that you can rule out the possibility that it's a sensory issue connected with the bathroom.



## Time Specialist Support is Recruiting in Manchester and Chester!

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## Brolly Sheets Protective Bedding Worth Nearly £70!



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Here's your chance to win a Brolly Sheet bed pad with wings PLUS a waterproof flat sheet, worth nearly £60.

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Oh and we've even persuaded those lovely people at Brolly Sheets to throw in a car seat protector (joy!) for one lucky runner-up. It fits anything up to and including booster seat size. Get them in green, red or blue at £9.95.

All you have to do is answer this question. You can find the answer on Brolly Sheets' website at [www.brollysheets.co.uk](http://www.brollysheets.co.uk)

**Q: Who is the mum behind Brolly Sheets and where is she from?**

Send your answer directly to [win@brollysheets.com](mailto:win@brollysheets.com) with AuKids in the subject header. All entries will receive a special discount as a thank-you! Competition closes August 31<sup>st</sup>.

*Good luck!*

No cash alternative. Usual AuKids terms and conditions apply.



Flat sheet

Bed pad

Car seat protector





# Please Can We



Here we are, us parents, doing our very best to make life happy for our kids. In twenty years' time, maybe our grown-up offspring will sit us down with a coffee and tell us all the things that they couldn't express when they were little. If only an older version of them could travel back in time to 2014, what would they be telling us?

We gave four adults on the spectrum an imaginary TARDIS. We asked them to travel back in time. What would *they* tell the adults around them? N.B. For nerds: Yes we know you can't go back along your own timeline, call it creative licence...)

## TIME TRAVELLER 1:

### Alis Rowe

Alis, aka the girl with the curly hair, is 25 and has Asperger Syndrome. She is an author and founder of the curly hair project. [www.thegirlwiththecurlyhair.co.uk](http://www.thegirlwiththecurlyhair.co.uk)



If I borrowed the TARDIS, I'd go back with a huge 'thank you' message to my parents. In countless ways, they gave me the freedom to be myself and this has led to confidence in my adult life.

The most helpful thing they did was to allow me to do exactly what I wanted. Not in a spoilt kind of way, but there was never any pressure to do well at school, no expectation to go to university nor any hurry to leave home and get a job.

My parents only - and very genuinely - wanted me to be happy. Whether that happiness came from my daily newspaper round, my four years at university, or the renovation of their lovely garden in order to build myself a gym so I could indulge in weightlifting (my special interest) in the privacy of my own home - my parents were cool with that.

**"I would go back to thank my mum, who has the patience of a saint, for all the times she has been there to answer my 'Why...?' questions"**

My dad has always (grudgingly!) put up with my insistence on having as many cats as possible. He does not like dogs but he puts his reluctance aside, always giving me the choice to have a dog, if it would lessen the stress I experience from daily autistic challenges.



I would go back to thank my mum, who has the patience of a saint, for all the times she has been there to answer my "Why...?" questions. For most of my life, we have had our chats while she's in the bath. She's never had those 'Five Minutes' Peace' (as in the children's book!). Instead, she is selfless, caring, and willing enough to answer, at length, the questions that each day provides me with. There are always questions. It is partly because I lack 'theory of mind' and partly because I exist on facts, logic and reason, over emotion and opinion.

I would tell them that I have always been grateful that they were flexible and laid back enough to accept that my meltdowns were (and are) just a part of me which should not be fought.

I absolutely cannot stand the smell of bananas so I am appreciative that they no longer eat bananas in the house. I try very hard to keep the house as clean and tidy as possible!

## TIME TRAVELLER 2:

### Emma Woodrow



Emma was born in 1953 and has autism. She worked in mainstream teaching, then as a special needs teacher, before becoming a lecturer and counsellor and is now researching autism. She wants to use a TARDIS to put into words how she felt as a child...

This is how it is. I know what I know and what I want to do. I just want to get on with things my way, in my own time. I am me. Please listen to me.

**"I'm sorry about the fruit rotting under my bed. It was an experiment."**

Do not let anyone tickle me. They *call* it tickling. It hurts. I hate it when they put their faces up close to my pushchair. It frightens me. That is why I bite them. I do not know who they are. They smell strong and make loud noises.

Don't make me stay in the room with loud things like washing machines. I won't get over it. I just need to be somewhere safe, curled up right inside my bed or wardrobe.



If I scream at rough towels or smooth or bobby clothes it isn't to upset you. It is because those upset me. They make my nails ache.

Just what is wrong with arranging things or counting in fours? Please don't move, throw out or give away my things without consulting me just because they look like rubbish to you. They are my collections. What is wrong with carrying things around? Just give me enough pockets or a rucksack, then it won't be any problem for you. They are my things and they make me feel safe and give me something interesting to do.

I'm sorry about the fruit rotting under my bed. It was an experiment.

What is wrong with spending time smelling carpets or fences or looking through pieces of green glass? It is interesting and much better than being shoved about by children. I don't want to play with them or have them invited into my garden.

How I wished for a time machine then; to get away, escape into adulthood or travel to a world ruled by animals, not people. Only, I read about that when I was 11 and the pigs were just as nasty as everyone else...



# Borrow That TARDIS?



## TIME TRAVELLER 3: Paul Isaacs

Author Paul Isaacs has classic autism and started working as an Autism Oxford speaker in 2010. He is now an author, trainer and consultant. His autobiography 'Living Through the Haze: Life on the Autistic Spectrum' was published by Chipmunka in 2012.

I was diagnosed in 2010 at the age of 24. As a child I had oral apraxia (I couldn't speak with my mouth), I have aphasia (this is a disturbance of the comprehension and expression of language) and also visual agnosias (seeing without meaning) which are a part of my 'Autism Fruit Salad' (Donna Williams 1995, 2005).

**"I would go back and tell them that my form of communication was meaningful despite it looking meaningless."**

This meant that I appeared deaf and blind. I think it would have been beneficial for me to have had a deaf/blind assessment to be able to rule out whether it was physical, neurological, or both.

In addition, it would have helped if I had been diagnosed early. This would have meant that my parents wouldn't have been blamed for my behaviour. This would have reduced social problems where I lived and also would have potentially changed my route to education and my mental health. With a diagnosis, I probably would have ended up at an autism base or specialist school where I could have accessed the help and support that I needed.

It would have been useful to have a range of strategies in

place to help me as well as support for me and my parents.

I would go back and tell them that my form of communication was meaningful despite it looking meaningless. The noises that I made were a way of trying to integrate with the world which is called 'pattern, theme and feel' - a term that Donna Williams uses for people who are communicating before they can be typically interpreted.

At three years old I was still a baby developmentally and I'm still developmentally delayed in both language and visual processing.

So, if I could go back in time I would say to adults around me: "Be open-minded, think outside of the box and do not blame. Be happy and give positive, meaningful strategies for communication and integration. Be understanding of my communication and sensory profile and see beyond my autism".



I did avoid 'learned helplessness' during these years as my parents allowed me to be as independent and functional as possible and saw me as a person rather than a set of traits or symptoms, which I thank them for.



## TIME TRAVELLER 4: Mark King

Mark is 33 and was diagnosed with Asperger Syndrome just last year. He works as a Service Desk Analyst for Newcastle upon Tyne Hospitals NHS Foundation Trust.

I have always wanted to be a Time Lord. After all, it would be easy to explain being out of step with society if I were merely a visitor from a different world.

Being an alien would explain why I am very sensitive to things other people don't notice, why I dress eccentrically, and why talking to computers is easily within my grasp but making small talk to a human is not.



Any explanation in the world (or beyond) would have helped my parents, who spent my childhood bewildered with the alien in his bedroom tapping away at computers and dismantling electronics. The world was very quick to tell them who I should be. My parents put tremendous amounts of effort into trying to close the gap between myself and 'normality'.

They seemed terrified that unless I fitted in I would end up alone, miserable and unsatisfied with life. They often worried that my 'bad' behaviour reflected badly on them and caused them embarrassment and guilt.

Autism wasn't in our family's vocabulary - we didn't know it had such an influence on me. We could have all lived at peace just knowing what it was that made me different.

If I could just borrow the TARDIS for a while, I would love to go back in time, sit them both down and start with two words: Don't Panic.

With the benefit of hindsight, I could show them that being different is actually amazing, and that trying to get my square peg into society's round hole was never going to make them or me happy.

I was diagnosed with Asperger Syndrome last year and every time I read up on the subject something from my past falls into place. Diagnosis finally felt like vindication to be myself and I wish I could have shared that with my parents while I was still young.

I would like to go back and show them who I am now; show them that although an autistic life is a road less travelled, it is still a road full of satisfaction, accomplishment and most of all happiness.

**"If I could just borrow the TARDIS for a while, I would love to go back in time, sit them both down and start with two words: Don't Panic."**

Using my time machine it would be tempting to give myself a view of things to come, too - having a family of my own, doing a job I love and thriving by learning to 'own' my condition rather than fight against it.

Letting autistic children just be happy to be themselves doesn't make you bad parents. It makes parents that are out of this world.



# Anchors Away!

## CONVERSATION SERIES PART 1



### Welcome to our first three-part series!

When we wrote about Social Stories™, we compared the social world to a strange land in which everyone seems to have a map except for our little Spectrumites.

Well, now we've got to the river in this strange land – that deep and daunting place where conversation skills happen. But how do you learn them when you have autism?

Let's set sail...

By Tori Houghton & Debby Elley

'Conversation rivers': we use the term to describe the easy ebb and flow of a two-way dialogue. What if this doesn't come naturally? Although you can remove obstacles downstream, the difficulties that autistic people experience with conversation aren't just floating on the surface of a river. They go much deeper, right to the very heart of the autism itself.

Whilst everyone else may be happily punting up and downstream, some of our kids on the spectrum are sitting in their boat looking lost, not sure how to



communicate or why. Some might be moving about just a little when they really want to. Others might be rowing like crazy but in the opposite direction to their boating partner. Then again, some might be rowing upstream very nicely but coming to an abrupt halt now and then every time they need to change direction.

This three-part series will focus on how to encourage your child to communicate.

• **ANCHORS AWAY:** In the first part of our series, we'll be looking at some of the basics of communication

• **WE ARE SAILING:** In Part Two next issue, we'll cover the beginnings of two-way conversation and how to encourage it

• **VOYAGE OF DISCOVERY:** In Part Three we'll be helping you to fine tune your child's conversation skills

It's worth pointing out that progression through each of these stages very much depends on the nature of your child's autism and their stage of development. Each part stands alone in its own right.

Wherever your child is at, we hope that you'll choose the part of the series that suits them best.

### What's This For?

In our story, we'd like you to think of your boat's oar as communication – the language we use (whether verbal or otherwise) to get where we need to be. Just as you use an oar to paddle up a river, language is also a tool.

The key thing to remember about autism is this: **the fact that language can be used to get you what you want is not generally apparent to a child with autism.**

Read that again, because it's massive.

This is because they lack 'theory of mind', or what we like to call 3D thinking – the ability to put yourself in someone else's shoes. It's also referred to as 'social imagination'. If you assume that the thought in your head is already in someone else's too, then you don't have to tell them a thing.

So, whereas another child might pick up an oar, automatically suss what it's for and start rowing, our pre-verbal child with autism still sees it as just a piece of wood. They might swing it about, experiment with it – but they may not be aware of its exact purpose.

### Avoid taking over the rowing for your child, however tempting that might be.

Our first job as parents, then, is to help them to learn the most basic purpose of communication; the ability to get what you want through sharing your thoughts with someone who isn't aware of them.

### Happy But All At Sea?

Initially, your child may sit happily in the boat and not even notice the oar. These children can be really easy – you may hear them referred to as 'passive'. Passive doesn't mean that their character isn't lively, it means that any communication they make is in response to yours, not started up by them (or 'initiated').

Unfortunately, that may cause us to delay getting them to use their 'oar' – they're happy enough as they are and we assume that they are okay with the direction that we're rowing them in.

Often we don't make it any better for our kids by swimming across to them and handing them everything they need over the side of the boat. In our quest to make them happy, we make it so easy! Yes, they'll be content for sure, but it's not going to help them learn to communicate. What happens when you leave the boat, eh?

There may be other kids who are so frustrated at not being able to get about in their boat that they bash you about the head with the oar! That frustration, caused by lack of communication, can often be positively channelled into supporting them to use their oar properly.

### Messing About In Boats

As you're sitting in your boat together, it's important to forget about what's upstream. Our first piece of advice is to relax about your pace.

Our second tip is to avoid taking over the rowing for your child, however tempting that might be.

Let them find out about this oar thingy for themselves. Pressure to communicate (which autistic kids can experience by being asked umpteen questions) is not very successful with kids on the spectrum. Letting them come to you is much more likely to yield results.

Your job at this point is to watch and observe. They might splash the water, so you might copy that. They might touch the oar and move it about a bit – you'd do the same.

In real life, this means being content to simply be with your child and pick up on the object of their interest, mirroring their sounds and actions. This technique is known as intensive interaction\* and it's very effective because it brings you into their world – suddenly the little rower realises that they have a team mate on board.



HE HAS  
OAR-TISM,  
GEDDIT?



In a 2010 study\*\* where parents were trained in intensive interaction techniques, it was found that the more in tune parents were with their child's non-verbal behaviour, the more the child made attempts to communicate. The researchers used the term 'synchronicity'.

So, the little person is starting to see you as a partner they can work with, rather than just an interesting object in the boat. Rowing is a high risk strategy and they need to feel that they can trust you.

## Gently Down the Stream...

When your child shows interest in the oar, you might help them to dip it in the water, showing them that if you put the oar in the water the right way, you move forward. The minute that they are successful with any attempt at all, you praise them like crazy!

In real life, this is known as 'modelling' and it's how we encourage our kids to communicate. Follow their gaze – what are they thinking, what are they looking at? Then label the thought with a word. If they make a mistake, avoid criticism but instead say the word correctly again, building their confidence.

Correcting focuses on what's being done wrong. Modelling shows how it's done right. For an autistic kid, there's a world of difference between a parent saying "No, not BOH – BOAT!" and "Boh? Yes, it's a BOA-T, that's good!"

## What's Upstream?

Very conveniently, you've placed an inflatable frog a few feet away in the river. Your little team mate loves frogs!

They don't know how to get to it, though - and a passive child might just look at it. A less passive child may splash about angrily using their hands.



The temptation for you at this point is to row quickly towards it for them and give them the darn frog before all hell breaks loose. But no, you've shown them how to use the oar and so all they need is the motivation (which you've provided) and a bit of a clue.

You're waiting for them to dip the oar in the water so that you can help out.

Look for that small signal that they need your help. A glance, a gesture, a noise...

Different children will need different levels of prompting. What would it take to get them moving that oar? In real life – what would

it take to get a slightly clearer signal that was directed at you? A picture to point at? An attempt at the word? A gaze or a general gesture?

Wait for the attempt before diving to the rescue!

In our boat story, our parent throws exciting things along the river constantly. Easy to get to, a triumph when obtained, they form part of a deliberate plot to encourage constant movement in the water.

We can use what we know motivates children to create these sorts of communication opportunities, then all they have to do is to use the oar as often as possible!

What sort of things can we 'throw in the river' to move our children along in the real world? Chocolate buttons in a box out of reach, a toy that works only with co-operation from an adult, bubbles, which a parent can produce on request. Any attempts to tell you what they need are rewarded.

## And You're Off!

Wow, what an effort that was! But once they start to use the oar with success, you can row with them, sharing the same oar.

Model the words, encourage the communication, reward often. Make it part of your daily routine. Whether

they use words, signs or pictures, the point is that they are communicating. It starts with what's called 'functional communication' – requesting something.

Gradually, this moves to commenting. As the oar glides slightly deeper into the water, you might notice your child's mood and body language and then, guiding the oar along, help them to put into words what they are feeling by 'modelling' the words. E.g. "LIKE the frog!" "Urgggh, don't like the frog!"

This is how conversation starts.

WATCH OUT FOR  
PART 2 IN OUR  
NEXT ISSUE!



\*Intensive Interaction is a common speech and language therapy tool in which parents and carers copy a child's behaviour and sounds, mirroring and responding to them. Since it is child focused, it uses the child's own motivation to build communication.

\*\*Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial - Jonathan Green, Tony Charman, Helen McConachie, Catherine Aldred, Vicky Slonims, Pat Howlin, Ann Le Couteur, Kathy Leadbitter, Kristelle Hudry, Sarah Byford, Barbara Barrett, Kathryn Temple, Wendy Macdonald, Andrew Pickles and the PACT Consortium – published Lancet July 2010

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Plus the hoodie, beanie hat, cap, school bag, pump bag, apron and even teddy bear!

The Aukids clothing range carries a selection of slogans dreamt up by the magazine team and designed to inspire tolerance and positivity! Quality clothing at fantastic prices made by our friends at [www.finsdesignandprint.co.uk](http://www.finsdesignandprint.co.uk). Order online. Kids' t-shirts for £8 and kids' hoodies for £14. Adult sizes also available.

A BIG thanks to Fins Design and Print for giving a percentage of each Aukids sale to our magazine.



[www.finsdesignandprint.co.uk](http://www.finsdesignandprint.co.uk)

# The Kindness of STRANGERS

A lot of our parents get pretty worried about other people's negative reactions to their kids' unusual behaviour. Yet there are as many good souls who want to help as those who are quick to judge. Here's some positive reactions – share your own positive stories on our Facebook and Twitter pages!



Read *Dear 'Daddy'* in Seat 16C Flight 1850 From Philly in the blog [www.goteamkate.com](http://www.goteamkate.com) - It'll bring tears to your eyes!



## Salon Saviour

'We have a fantastic hairdresser who clears the salon for our son who's 12 with autism. She even opened up on a day they were shut between Christmas and New Year so he could have a haircut. For the first time ever, he's had his hair cut regularly over the last six months, and he's calm and she's very flexible. She blocks off time before his appointment and time after to make sure there's no one else in the salon, and sends the rest of the staff into the back of the shop.'

Faye



## What To Do When Your Child Has a Wobblor in Public

- 1 Before you go, let your child know where you are going (photo if poss) and how long the visit will last - stick to it faithfully. Show them the reward they'll get afterwards in picture form. Keep praising them when they're being quiet and patient. 'Good waiting! Well done!'
- 2 Prevent a wobbler. Go to [www.autism.org.uk/living-with-autism/out-and-about](http://www.autism.org.uk/living-with-autism/out-and-about) for some preparation tips on common visits to doctors, dentists etc.
- 3 Have some distraction aids ready for queues.
- 4 Shameless plug: Put little 'un in an AuKids T-shirt with slogan (e.g. 'I was born with autism, the cheeky smile is all my own work') - strangers will get the message quickly and positively.
- 5 Sometimes kids are dragged through an aisle

quickly when something has fascinated them. Tell them they have 5 minutes to have a good look. If you know it will be really distracting, leave it till last.

- 6 If they want something they can't have, tell them when they WILL be able to have it instead of an outright 'no' (which means 'forever' to an autistic child). Make a big deal about writing down the name of it and price, saying you're keeping it in your special book so that you can remember it for when it's time to buy a present.
- 7 Bring a small towel with you so that you never have to go near a hand dryer!
- 8 Understand what makes sensory overload for your child. Sometimes ear defenders can be useful because the overload comes from all senses, and switching just one channel to 'low' can prevent meltdown.

## Santa's Little Helper

'One Christmas a few years ago when my son was still in a buggy I had done most of my shopping online. I just had to get one last present for my dad. My son was totally overwhelmed by the crowds, noise and decorations and started to have a very screechy meltdown. This was before he was diagnosed and obviously now I know it was sensory overload. Many people gave us dirty looks, tutted at us and one nasty old lady actually shouted "Shut him up," right in my face. I ended up in tears trying to calm him down. So there I was, sobbing in the gift aisle of the Birkenhead branch of Boots, when a fellow customer came over to me and asked me if I was okay and if there was anything she could do to help. The couple of minutes she spent with me meant so much and completely restored my faith in humanity.'

Andie



## Not All Stares Are Disapproving

'My son Matt and I went to Formby beach by train in a rain storm three days before Christmas (his choice of course and my fault for asking what we should do but I was rewarding a good sentence!). We got soaked because Matt had an amazing time jumping over waves. So we were on the train dripping wet. An elderly couple got on and sat opposite us. Matt doesn't sit still and talks loudly and his speech isn't so clear and is mostly one or two words. This couple were staring at him and I was about to give them my 'What are you looking at?' stare back when the woman asked if he was autistic, and started to tell me all about autism in the Sixties. I didn't get the full story of why because we reached our station, but sometimes people are staring out of recognition and not disapproval.'

Lynn



## Noteworthy Hero

'My son had a meltdown going to school last Friday. A lady who we didn't know happened to be in the area while staff were helping to calm him down. She produced this tiny colourful notepad out of her pocket and handed it to him. I held my breath waiting for him to throw it... He stuffed it into his pocket and instantly started to calm down. That day he wrote his teacher notes on it about how he was feeling and wrote me notes about how he'd had a good day. I saw her and was able to thank her, I don't think she realises how much her kindness meant to him and also to me, though.'

Polly

- 9 Be realistic about what you can achieve with little 'un in tow and don't plough on if they're distressed. Leave as soon as you can and sit somewhere quiet. Take a breather, you both need it. Usually things go from bad to worse without a cooling down period.
- 10 If the worst happens, calm yourself down and breathe slowly. Talk in a calm and slow voice to the child. Forget everyone else. An agitated reaction and a hurried tug of the sleeve will make things worse.
- 11 Don't try to reason with your child once they're in meltdown mode; extra conversation is overload. Just use calming phrases.
- 12 Don't interpret someone's glance as 'evil'. It may just be curiosity or concern and remember you'll be feeling sensitive if junior is making a fuss – it's natural.
- 13 You can buy an Autism Alert card from the NAS for £2.50 which is a mini information pack. Hand it over at difficult moments. [www.autism.org.uk](http://www.autism.org.uk)
- 14 If someone comments rudely, think of what your child is experiencing and compare it with something the onlooker is familiar with. For instance, ask them 'Do you know what it feels like to stand underneath a speaker at a rock concert? That's how he feels right now. He has autism and his experience is very different to yours.' If you can manage it, it's far better to educate than to start a row. (But you can mentally tell them where to go!).
- 15 We know this is tough – if your child is just being generally noisy as opposed to meltdown, SMILE! Show the world that this is normal behaviour for them, they'll soon look away. They are more interested in their own shopping.
- 16 Try not to worry about other people's reactions. Anyone who takes time out to criticize a parent in a public place must have a very sad life indeed. This is probably the most exciting thing they've done all day.



# Getting Their Wires Crossed



Why are some of our kids so over-sensitive to touch and what can we do to help them? The answer is *really* complicated and extremely technical. It'd take one of those horribly long books with no diagrams and lots of tiny words. Or, it'd take our expert Occupational Therapist Breanne Black, a master of plain speaking - with a bit of AuKids magic thrown in.

## TOUCH

Touch is our first language; it is the first system to develop in the womb. It's the primary way in which we make contact with the external world and a protective system which alerts our body to potential danger.

The tactile system is thought to be of great importance when determining behaviour, so when things don't work well, it has a negative impact on how someone perceives and responds to their environment. It can impact on behaviour, learning and all aspects of daily life.

So, touch is critical to our interaction with the world.

## THE TACTILE SYSTEM

Tactile sensory input carries information from the body to the Central Nervous System (CNS).

This information is transmitted along two different pathways.

Think of the pathways as two phone lines.

The Dorsal Column Medial Lemniscal (DCML) phone line, we'll call phone line 'A'.

The Anterolateral System (AL) phone line, we'll call phone line 'B'.

Each phone line carries different sensory messages.

## PHONE LINE A

**TACTILE, VIBRATORY AND TOUCH/PRESSURE PROPRIOCEPTION**

Phone line 'A' carries primarily tactile, vibratory, touch-pressure and proprioceptive information. Proprioception is the sense of your own body - knowing where your limbs are without looking at them. This phone line aids tactile discrimination or perception (finding the Cola bottle in the pick 'n' mix bag in the cinema without looking, for instance), detection of size, form, contour and texture.

## PHONE LINE B

Phone line 'B' carries information which mediates pain, crude touch (that's very light touch) tickle and temperature.

A very important difference between the two phone lines is that phone line 'A' has the power to inhibit or dampen down the messages carried along phone line 'B'.

**PAIN**

## WHAT CAN GO WRONG

Constant firing of phone line B (carrying information about pain, very light touch, tickle and temperature) means that someone could have poor awareness of temperature, therefore struggle to regulate their own. AuKids' distributor Tim can always be seen in short sleeves, even in the snow!

Other common functional difficulties include 'tactile defensiveness' - when touch is incorrectly interpreted as being unpleasant or harmful. It can occur when phone line 'B' is constantly firing information about pain and temperature, so all touch is interpreted as one of these.

Common difficulties include:

- Sensitivity to touch
- Dislike of labels in clothing
- Overreacts to touch
- Dislikes messy play
- Dislikes standing in lines next to others
- Dislikes walking barefoot
- Dislikes teeth cleaning

## USING PHONE LINES CAN HELP!

As all these difficulties occur as a consequence of excess firing of phone line B, activities which dial up phone line 'A' have the power to override and dampen down phone line 'B'.

Activate phone line A by:

- Deep pressure
- Stretch
- Vibration



If you stub your toe on the table, phone line 'B' starts to transmit pain signals. You automatically rub your toe, which activates phone line 'A', as the rubbing is touch pressure. Phone line 'A' dampens down phone line 'B', so the action of rubbing helps to dampen down the pain. Clever, isn't it?



**Does your child hate brushing their teeth?** The use of a manual tooth brush with fine filaments could be interpreted as light touch, so this information would be carried along phone line 'B' and someone who has sensory processing difficulties may interpret it as painful, tickly or hot/cold.



An electric toothbrush that vibrates will dial up phone line 'A' (more powerful), hence dampen down the negative response of phone line B and make your child more tolerant of the sensation.

**Does your child dislike messy play?** Paint may be interpreted as light touch, so will travel along phone line B, and may also be felt as painful, hot/cold or tickly in an individual with sensory processing difficulties. So try pushing hands together, squeezing hands, pushing hands against the wall. This provides deep pressure input, dialling phone line 'A' and dampening down the over-protective response of phone line 'B'. It will help to desensitise the hands, ready for exposure to textures which may previously be interpreted as unpleasant.



# The Last Word

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

## The Autism 'Snob'

There are two types of autism snob. Proper snob, and inverted snob.

The 'inverted autism snob' represents the type I sometimes bumped into at support groups when my twins were small. They are the 'anything you can do, I can do better' variety. In this case, though, they have the monopoly on suffering. You think you've got it bad? You ain't heard nothing yet. I remember mentioning to someone that Bobby (who at this time was about three) would head butt the side of his cot, the front door and even the floor with alarming frequency.

"You think that's bad," said one parent. Well yes I do, actually, I thought. "Mine cracked her head open and we had to go to A & E and now she wears a special helmet."

I said: 'Wow that's terrible,' and then gave her one my best dark looks, the one that can barbecue beef burgers. I wanted to say it, but I didn't. I wanted to say: 'Look, just because your kid has a ward named after them in the local hospital, that doesn't mean to say that I'm not having a rough time of it, too. I came here for support, not a game of trumps'.

In my view, there's not really a place for one-upmanship in support groups. We're all in the same boat and if you're going to start bragging about how your life is so much worse than everyone else's then others will soon bail out on you. If you run a support group where you don't play host to the world's greatest martyr, then pat yourself on the back.

I hold my hands up - I'm guilty of the other type of 'proper' snobbery, the one where you completely underplay the autism. Sometimes, Bobby can have a great little chat with me. But if he fails to perform at the top of his social potential, I'm liable to make out that he's only autistic part-time. "Ah,

this is because he's in a new environment. Actually he's brilliant when he's in his comfort zone."

Of course he's brilliant in his comfort zone you dimwit, I later chastise myself. That's what autism IS. Comfortable and coherent one minute, echolalic and disjointed the next. Saying "He's not always this autistic," is like saying "the traffic's not always this bad" when you're driving on the M25 at 3pm on a Bank Holiday. Anyone who isn't aware that autism changes according to the circumstances probably isn't worth the energy of the explanation.

Course, my kids always choose their moments to show just how far they haven't come. Usually it's when I'm boasting about how great Bobby's social skills are coming along. That's when he'll decide to totally blank the visitor without so much as an upward glance from the iPad, forcing me to cajole a greeting out of him through gritted teeth. And, I'll just be smiling to someone about Alec being so easy and laid-back when he'll let out a high-pitched scream and hold the note for about as long as Tony Hadley managed in 'Gold', breaking every living room window on our street in the process.

I'll mutter something about him going through a phase (one that's lasted roughly ten years) and smile apologetically as the newcomer leaves the house, trailing their shattered eardrums behind them.

Thinking about it, none of us should be upsizing the autism or downplaying it either. Let's decide to be cool enough just to shrug and say 'there are good days and bad days', and leave our daft egos where they should be - relaxing on the sofa asking for neither sympathy nor applause from others.



## Together for autism

To support your child's journey through childhood into adulthood our ASC specialist services include:

- Inscape House School • Step-up course at Bridge College •
- Community Support and Short Breaks •
- Shared Care and full-time Residential Care •

Together we work across the autism spectrum from birth to adulthood. We provide independent diagnostic and specialist assessment, speech and occupational therapy assessment and delivery. We also provide consultancy.

To find out more please contact us  
[togethertrust.org.uk](http://togethertrust.org.uk)  
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Combining the latest techniques and practices, HELP reduces the need for high-risk interventions by focusing on how our actions can positively shape the well-being of all those who use our services.

Find out more about HELP and our positive and progressive services: visit [www.hesleygroup.co.uk](http://www.hesleygroup.co.uk) or call us 0800 055 6789.



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