

# Aukids®

Issue 23  
Spring 2014

£15 annually  
Available from  
[www.aukids.co.uk](http://www.aukids.co.uk)

**Positive Parenting for Children with Autism Spectrum Conditions**



## **Colour Coder**

The teacher turning chaos into clarity



## **It Takes Two**

The parent-professional dialogue



## **Big Break**

Summer's nearly here, be ready!



**PLUS**

**Discounts, prizes,  
readers' letters and  
much more!**

# Letter from the Editors

Welcome to the spring edition of

# Aukids!



The picture above shows co-editors Debby Elley and Tori Houghton with children's shoe-fitting assistant Jane Mellor at the Cheadle branch of John Lewis. The AuKids team was only too happy to endorse the store's autism friendly shoe-fitting service and we're giving their staff some tips on how to progress the initiative. Currently, parents who have children with autism can let the store know in advance and are led to a quiet changing room for a fitting with Jane, who is even working on developing puppets wearing their own footwear to aid the communication process! If successful, this will be rolled out to other John Lewis stores. John Lewis – we salute you!

April 2<sup>nd</sup> was World Autism Awareness Day, so we teamed up with Nice Ice café and ice-cream parlour in Cheadle, Stockport. Owner Brian was delighted to promote the day by letting AuKids take over the shop with our now famous 'autism sundae' feature. Here's Tim Tuff, our team member and autism advocate, making sure that the posters are in place!



If you'd like to get hold of any of our posters contact us at [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com) An A3 ice-cream sundae poster costs £1 and our autism friendly advice one can be emailed to you free of charge.



The AuKids team has been busy with a series of talks. Debby and Tori's talk *Positive Parent, Positive Professional* had an enthusiastic reception at its debut at a conference for professionals in Wigan, hosted by the council. Tim joined the team at Wigan to give his new talk, *Ten Things I Wish You Knew About Me* - a personal perspective on autism from the inside, which proved very popular too.



If you fancy helping AuKids to raise some money and you'd like to host one of our talks, please do contact us at [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com)

See you in July!

*Tori & Debby*

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



**Get Shirty:** Here's the latest design in our AuKids hoodies for friends, family and carers. To see more check out [www.finsdesignandprint.co.uk](http://www.finsdesignandprint.co.uk) and have a look at their advert on the back page.

## 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 and training.



To find out more please contact us  
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facebook.com/SupportTogetherTrust    twitter.com/TogetherTrust

[enquiries@togethertrust.org.uk](mailto:enquiries@togethertrust.org.uk)

**together**  
trust



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121215

## COMPETITION WINNERS FROM ISSUE 22:

- **Coach book:** Julia Maunder, Stockport; Donna Cooper, Trowbridge, Wiltshire; Sarah Williams, Hampshire; Kevin Whincup, West Wimbledon, London.
- **Window-safe restrictor:** Angie Stuart, Ross-shire; Jamie Raine, Northumberland and Jo-Anna Dem, Berkshire.

Whilst the products and services advertised in AuKids are recommended to us by readers, we are not an industry inspector or regulator. We advise readers to seek independent advice from regulatory bodies before signing up with a new service provider and to check that products and equipment meet with industry standards.

The opinions expressed in AuKids magazine are those of the contributor. Please seek medical advice before embarking on any therapy or behaviour intervention. All articles are copyright AuKids.

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## Number One Choo Choo Choice

Dear AuKids,

When it was my son Edward's third birthday, we went to Mangapps railway museum in Burnham on Crouch, Essex and I thought I'd share it with you. Like a lot of autistic people he is obsessed with 'choo-choo trains' as he calls them. It was fairly cheap to get in and the cafe and ticket area are train carriages which is rather cool. We got endless rides on their steam trains which was lovely - and we tried out all three classes, LOL! To my surprise, though, Edward's interest also extended to the actual museum. He looked for ages at the buffers, signs and signals and he loved it all. In the museum you could go aboard all sorts of trains, even the driver's bit. It also includes an underground one. To finish off, there was a huge toy train set to play with, which he did for over an hour.

From Katherine Gibbinson, Essex



Mangapps Railway Museum, Southminster Road, Burnham-on-Crouch, Essex, CM0 8QG Tel: 01621 784898. Web: [www.mangapps.co.uk](http://www.mangapps.co.uk)

## Celebrity SPOTLIGHT



Joy

Age: 5 years 8 months.

Diagnosis: Autism.

Joy by name, joy by nature! People describe me as delightful, joyful, smart and happy. I want to be a superstar. Some things like reading are taking me a bit longer to learn than my peers. I'm like the tortoise in the story The Hare and the Tortoise. I'll get there in the end and win the race!

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

I like: Playing with my support worker Hannah and her dog Lady, cooking, playing with teddies, shopping and making things.

I dislike: The dark.

## Sundae Praise

Dear AuKids

My mum has just picked up Issue 20 of AuKids and is LOVING it. She has been in secondary mainstream education for 30 years and has just made the jump to primary education in a special school, which has just given her a new lease of life. Having read the Ice Cream Sundae article she is adamant that every teacher (mainstream and special) needs to see it! Ellie Grace Carrick, Salford



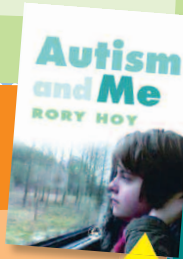
Dear Ellie - thanks so much for your kind reaction, and your mum's. An A2 poster version of the ice-cream sundae feature is available from AuKids for £9.70 incl. P&P. Just write to us at our usual address.

## Rory-ing Success

Dear AuKids,

I thought I'd take a moment to share with you an excellent DVD that my son's SENCO lent to me, it's called 'Autism and Me' by Rory Hoy - it's totally through Rory's eyes as he explains what his autism means to him. It's very light-hearted and I found it heart-warming too, it's only 20 mins long and is a nice insight into daily life. I would recommend it to all parents and even children, especially older ones.

Regards, Gina Gannon, Kent



## Film Fans Love ASD-Friendly

Rhys, 8, who has autism, and his sister Rihanna, ten, who has sensory integration difficulties, have been going to autism friendly screenings (AFS) in Tunbridge Wells for two years. Rhys doesn't have the patience to sit down for the length of a long film, he likes to move around and play with the seats.

Their mum Barbara Powell wrote to us to say: 'When we saw AFS advertised, we went as a family and it was brilliant. Rhys had never been to the cinema before and even though he doesn't always watch the film, he loves sitting in the big chairs with his popcorn on his lap looking up at the big screen. It was very touching to see this for the first time, and still is. 'Everyone there is like minded and in

the same boat; there are children making noises and no one judges you, it feels more like you're among friends. 'The screenings are definitely helping them in the long run; they're getting used to being in a public environment and mixing with the community'.

Dimensions, a not-for-profit support organisation, runs Autism Friendly Screenings on Sundays throughout each month with ODEON, Cineworld, Vue and Showcase. The organisation also runs a children and young people's service called Dimensions Buddies. For information visit [www.dimensions-uk.org/autismfilms](http://www.dimensions-uk.org/autismfilms) and [www.dimensions-uk.org/dimensions-buddies](http://www.dimensions-uk.org/dimensions-buddies)



## Newshound

North West Tonight newsreader Annabel Tiffin recently visited Outwood School in Stockport to talk to the children about her work. Co-editor Debby's son Bobby was only too happy to have his photograph taken with her, and insisted that she take a copy of his favourite magazine - AuKids - to read! Who needs a public relations officer when one small ten year-old can do the job for you?



## In A Spin Over DVD

Dear AuKids I have just read your latest magazine and so has my son (aged 11 with Asperger Syndrome). Both of us exclaimed when reading the 'Inside Cloud 9' section: 'There is a washing machine DVD!'. Like Tracy Winter with her son, we have spent many an hour at Curry's looking at washing machines when my son was much younger! If only we had known about the DVD. Loved the magazine.

From Sarah Polack, chair of The Avenue support group, Bedfordshire.



Washing Machine Impressions DVD, available from Amazon.

## Bits 'n' Bobs

Inclusive entertainment comes in the form of Circus Starr which is touring the country this May. The circus prides itself on being autism friendly. For information look up [www.circus-starr.org.uk/tour-news/uk-tour-dates](http://www.circus-starr.org.uk/tour-news/uk-tour-dates)

Recently AuKids wrote to a local newspaper to voice our concern about a local family group that has been forced to close due to a lack of Lottery funding. We have produced a blueprint version of the letter, including a quote from AuKids, that you can send to your local newspaper, MP or councillor if you need to voice a similar concern. Write to us at [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com) if you'd like us to email you a copy.

**25% OFF**  
New Sticker  
Sets!



Last year we featured the Tom Tag by Orkid Ideas, colourful tags each with spaces for you to pop plastic buttons with interchangeable stickers on them. The tags (one for each day of the week) can be attached to a child's school bag - a brilliant idea to promote organisation skills by reminding youngsters what they need to pack for the day ahead without relying on you to do it for them.



Building on the success of their first product, Orkid Ideas now has two new sticker ranges to enable TomTag to be used as a scheduling tool. The new sticker packs cover school timetable and self care routines and both sticker sets use images from Widgit and can be ordered with or without words under each image. For further details check out [www.orkidideas.com](http://www.orkidideas.com).



Packs ordinarily retail at £4.00 each but AuKids readers can claim a 25% discount - simply use the code:

**AUKID25**

**WIN**  
Aiden the  
AuKids  
Teddy Bear!



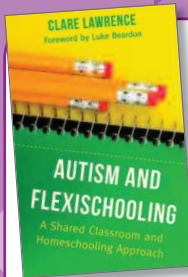
They're new, they're extremely cute and now you can win one! Aiden the AuKids teddy bear can sport T-shirts displaying any of our AuKids slogans. Choose either navy, red or fuchsia T-shirts and any of these slogans in sparkle, plain, neon pink or neon green lettering:

- ★ Stand aside: I have the special powers of autism
- ★ Stand aside: I have the special powers of Asperger's
- ★ God created autism to help offset the excessive number of boring people
- ★ Autism: If it's good enough for Einstein, it's good enough for me
- ★ I'm not difficult, I'm exotic
- ★ I was born with autism, the cheeky smile is all my own work
- ★ My friend's on the autism spectrum, apparently I'm cool for a neurotypical
- ★ I don't have autism, but I know a guy who does

To win your teddy bear, worth £9.99, just spot Aiden hiding in this issue! Send your answer to [auidsmag@gmail.com](mailto:auidsmag@gmail.com) or write to us at the usual address, no later than May 31<sup>st</sup> 2014. Three lucky winners will be selected at random.

You can buy a teddy bear as well as hoodies, T-shirts, hats and bags with the same slogans at [www.finsdesignandprint.co.uk](http://www.finsdesignandprint.co.uk). For every T-shirt sold, £2 goes towards supporting AuKids.

# Reviews & Prizes



## BOOK

**Autism and Flexischooling: A Shared Classroom and Homeschooling Approach**

By Clare Lawrence  
Published by Jessica Kingsley  
£14.99 • ISBN 9781849052795

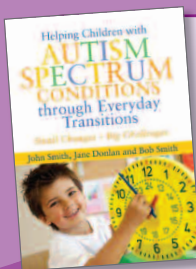
The author is a parent of a child with autism. Her own experience and knowledge of autism make it an interesting and informative read.

The idea of flexischooling is that the child is taught both at school and at home, which

would particularly suit many children with autism. The pitfalls and difficulties were highlighted by the author, who also sets out a range of arguments supporting flexischooling. The book is a really interesting read, peppered with personal experiences - and it made me consider flexischooling as a possibility. It also outlined how to set up a flexischooling system in order to enable it to work well with the child's school.

Although it's an easy introduction, it didn't go as far as setting up lesson plans, following the curriculum and teaching strategies. But that is probably another book in itself.

Melodie Blake  
AuKids readers' panel



## BOOK

**Helping children with autism spectrum conditions through everyday transitions: Small changes-Big challenges**

By John Smith, Jane Donolan and Bob Smith  
Published by Jessica Kingsley  
£13.99 • ISBN 9781849052757

Written by the parents of co-author Bob Smith - who is on the autism spectrum - this book provides strategies to help manage the many changes faced daily by children with autism and the difficulties these changes can cause.

The book seems to be aimed at parents of children with Asperger's and high-functioning autism.

Written in a friendly style with clear sections, it begins with an introduction to autism, sensory needs, emotions and why change is so difficult, with the theories explained clearly and simply.

Examples from the authors' own lives are given alongside their son's comments on how their strategies have helped him to cope.

The strategies involved the use of scripts, (similar to Social Stories™), signs and sketches as preparation for change and I will use some of them with my own son.

A positive but realistic view from the authors show that they have genuinely lived this journey and they give lots of friendly encouragement to the reader.

Melodie Blake  
AuKids readers' panel



## BOOK

**The 1<sup>st</sup> Comic Book**

By Alis Rowe  
Published by Lonely Mind Books, London  
£14.99 and £6.37 Kindle edition  
ISBN 978056269317

Author and cartoonist Alis Rowe, (or 'Rent-A-Quote' as we call her) is a force of nature. This 25 year-old superwoman has Asperger's and has made it her mission to help neurotypicals to understand how Aspies (in particular Aspie women) really think and feel. She communicates it through the medium of cute cartoons including a stylised self-portrait (the curly hair and the cat both belong to Alis!).

The cartoons are so distinctive and so prolific that the Curly Hair project has become somewhat of a brand and an internet phenomenon to boot. Alis self-funded this first publication, The 1<sup>st</sup> Comic Book, through a Facebook fundraising campaign. Since she's starting to get noticed in high places, I've no doubt that her later work will soon be in the hands of major publishers.

The book consists of 26 cartoon scenarios depicting neurotypical behaviour and the Girl With Curly Hair's responses via thought bubbles. Since the scenarios reflect the author's own life, they cover misunderstandings at college, work, with family and in relationships. They show how

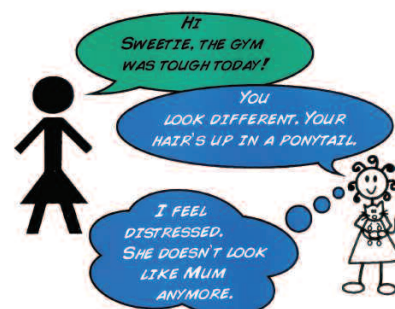
anxiety and routine often rule the head and indicate how another's well-meaning encouragement to 'socialise' can be genuinely unwelcome.

This isn't for kids but it's a great one to add to the smile file if you already know someone with Asperger's and will enhance the layperson's understanding no end.

Check out [www.thegirlwiththecurlyhair.co.uk](http://www.thegirlwiththecurlyhair.co.uk) for ebooks including *Asperger's for Children and their Parents*, *Asperger's Shutdowns and Meltdowns* and *Asperger's Syndrome*.

Debby Elley  
Co-editor

**THE GIRL WITH THE CURLY HAIR**  
IS WAITING FOR HER MUM WHO HAS JUST  
FINISHED AT THE GYM.  
APPEARANCES CAN BE CONFUSING.





**SPEAKER**  
**Phoebe Caldwell**  
Hosted by Autism Oxford  
www.autismoxford.org.uk  
25<sup>th</sup> January 2014  
The Kings Centre, Oxford

**Phoebe Caldwell is an expert practitioner in Intensive Interaction and has over 30 years' experience as a practitioner with people whose severe learning disabilities are linked with behavioural distress.**

Usually it takes me no time to write a review, but in this case I became stumped by the enormity of the challenge. It's difficult to put into words just how inspiring we found Phoebe Caldwell. Instead, I came up with lots of interesting things to do on Facebook. When I finally stopped procrastinating, I came up with an analogy.

Remember the part in Star Wars when Luke Skywalker first meets Yoda? The cinema bears witness to the young Jedi discovering the power of his own potential as he gradually realises just what the Force is capable of?

Well, that's how it feels listening to Phoebe talking about how we can alleviate sensory confusion and be successful with the technique known as intensive interaction. You think you know about autism? Then witness the master at work. It was like watching an autism 'whisperer'. At one point, when watching a video of her working with an adult whose transition from non-verbal to verbal happened on screen before our very eyes, I actually had to remind my mouth to stay closed.

So how does she approach those people on the spectrum whose potential is profoundly compromised by sensory confusion?

Again, that's tricky to get across in a naff little review like this, but I can share the gist. Phoebe is an expert at interpreting the neurological symptoms displayed through a person's body language. From that she can gauge the type of sensory confusion or pain that they're experiencing. Once their stress

levels are lowered, she uses intensive interaction to engage them and facilitate communication.

In her talk, she outlined the sorts of sensory disorder that people with autism experience, showing one short video - created by an adult on the spectrum - that simulated the experience of sensory overload.

We are all so used to acknowledging that people on the spectrum have sensory problems, without really thinking about what that could mean for them. We don't intend to be glib when we say it, but when you hear a range of first-hand experiences of sensory dysfunction described in detail, you wonder how some people manage to get out of bed in the morning, let alone socialise. Her powerful examples made us sit up and focus.

When describing sensory overload, she explained that it is the autonomic nervous system (ANS) which controls heart rate, breathing and all our involuntary responses. Sensory overload can cause this system to break down in autistic people, as the ANS misreads a situation and responds as if threatened. Even emotions can have an effect on this system, more profoundly so with autistic individuals.

“ .....  
**You think you know about autism? Then witness the master at work. It was like watching an autism 'whisperer'.**  
..... ”

A person's strategies to combat an 'autonomic storm' (the neurological term for sensory overload) can include avoidance, freezing, exit or stimming (repetitive behaviour). They need space and time to organise the overload and Phoebe advises using objects of reference (that's a relevant object like a beaker to indicate that a drink is on offer) rather than speech to avoid overloading them further.

One lovely analogy she quoted was from an autistic adult who described his brain as a 'dial up modem' instead of a cable one. Everything takes longer to process and the system can easily become clogged.

We loved her translation of the term 'challenging behaviour'. It's really 'distressed behaviour', she insists, and is almost always caused by sensory overload.

Phoebe's first priority, therefore, is in attending to the cause of

stress to help give an individual some coherence.

She outlined a variety of tools that can alleviate the symptoms of some sensory dysfunction - including small massagers along the neck and spine to relieve sensory pain and the use of Irlen lenses (www.irlen.com) for visual disturbances, which were also advocated by one of Autism Oxford's amazing speakers, Paul Isaacs. (Paul has also contributed to a chapter in Adele Devine's book on them - see Page 8). If you're interested in reading more, she details other interventions in her new book, *The Anger Box*, for which we've bagged an offer for you (right).

The 400-strong audience of parents and professionals were later treated to a masterclass in intensive interaction through a number of video clips. I'll admit, I'd always thought that intensive interaction was just about copying. Phoebe uses the term 'responding' and there is a difference - she mimics, but at the same time she takes up that conversation - either through body language or through sounds - and brings it a little step further by adding to the non-verbal conversation.

Since then, I've used this 'responding' with Alec and it's been a great success and kept our little chirpy chats going for longer. Watching her endless perseverance has given me renewed patience with my interactions with my own son, who at ten remains pre-verbal but has good understanding.

In some cases where intensive interaction looked tricky, film clips showed Phoebe mirroring a child's breathing movements, which also seemed to have a calming effect.

Tori said her biggest eye-opener came when Phoebe overstepped the mark with an adult who had proved aggressive in the past, and he aimed a small punch in her direction. She punched the sofa she was sitting on to physically acknowledge his emotion in the same way - and this proved really key in calming him down.

The lesson here is to align your feelings with another's to get emotional engagement; it's important to validate negative feelings.

Well, I could go on for hours but unfortunately I've run out of page. Instead, I'd recommend watching some of Phoebe's work online and buying her book, which covers much of the material from her talk. This is easily the speaker I've learnt the most from - I'd highly recommend travelling to listen to her.

**Debby Elley**  
Co-editor

**WIN**  
**A Copy of the Anger Box**

To win a copy of Phoebe Caldwell's brand new book, worth £12.95, simply answer this question:

**Q: In 2011, which university awarded Phoebe Caldwell an Honorary Doctorate of Science for communication with people with autism?**

The answer can be found at [www.pavpub.com/the-anger-box](http://www.pavpub.com/the-anger-box). Send your answer to AuKids at PO Box 259, Cheadle, Cheshire, SK8 9BE or by email to [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com) with 'Anger Box' in the subject header. Entries to be in no later than May 31<sup>st</sup> 2014. The winner will be chosen at random and contacted by Pavilion Publishing.



**Aukids Reader Discount**

Take advantage of a £3 discount on *The Anger Box - Sensory Turmoil and Pain in Autism*, which normally retails at £12.95. Simply go to [www.pavpub.com/the-anger-box](http://www.pavpub.com/the-anger-box) and use the code:

**SEN3**

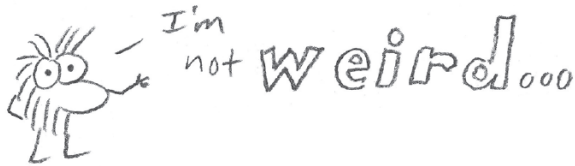
in the voucher code box at the checkout.

Pavilion Publishing and Media Ltd (27<sup>th</sup> Jan 2014)  
ISBN: 9781909810440

To watch films of Phoebe Caldwell at work and find out about her other publications, look up [www.phoebecaldwell.com](http://www.phoebecaldwell.com)



“How and when would you recommend I tell my child about their diagnosis? I am nervous about discussing it.”



I'm just **wired** differently!



Illustration taken from *Dude, I'm An Aspie!* by Matt Friedman published by www.lulu.com, ISBN 9781300027959



**Debby Elley**

BA Hons

Co-editor of AuKids and mum to autistic twins Bobby and Alec, who are ten.

I love author Jennifer O'Toole's attitude – she virtually suggests throwing a party for a child with Asperger's with the announcement 'Congratulations – you have an awesome brain!'

The point is, any chat shouldn't be full of foreboding (kids worry big time) and in my case it was never a sit down talk either. I suggest it's more casual than that. When Bobby was small, if he struggled with something, I used to mention that it was because his brain worked a bit differently. I never talked about disability (to me he's not disabled) – I just talked about the variations in the way that his mind worked.

Once he got a bit older, and was mature enough to take it on board, I explained that it was autism. I kept it nice and concrete, giving examples rather than speaking in general terms. 'Remember when you got so upset really quickly that time? That was because your feelings get way too big for you to handle really quickly, and that's the autism.' This is more meaningful than telling them they have a

social communication disorder! Reinforce that the great thing is that we know it's autism, which means we can help with those things.

The whole 'we don't either' thing is very important. Also, stress the positives that come with a brain that works differently. You're good at some things, you struggle with others. The main thing is plenty of reassurance and a casual demeanour rather than oodles of sympathy. You are not breaking news of a terminal illness and it should not feel like you are.

Bobby is only ten and he still doesn't have a detailed concept about what autism means, after all it's a very complex condition. What he does understand is that he has a brain that works differently, that it won't stop him from doing anything in life and that he's wonderful the way he is. He's taken this message with him wherever he goes and wastes no time in letting people know that he's great the way he is. This giant dose of confidence will stand him in good stead when it comes to dealing with those idiots in later life who may try and make out that his autism is a bad thing. Job done.

As some of you will know, my twin sons sit at either end of the spectrum, so I've treated this subject differently with both of them.

From the start, my view has always been that if you don't tell a kid (one who has the capacity to understand) why they're different, you lead them to assume that they struggle in some things because they're odd or stupid. Since number one priority for living and learning is being happy and having confidence in your abilities, the subject needs to be openly unfolded - but in a careful way.

With Alec, the answer was simple.

Alec, who is pre-verbal and at a special school, doesn't have the capacity to take on board the concept of autism. He knows he's different to his brother and all that needs to be reinforced in his case is the fact that he's loved for who he is. He can absorb the concepts of love and acceptance just fine and that's enough for us and for him. I tell him often that I'm proud of him and he has learnt to take pride in small achievements.

In Bobby's case, there has never been a time when he hasn't known that he has autism, although my methods of communicating this to him have become more sophisticated as he's got older. You do have to be in the right place yourself in order to talk about autism. By this I mean that you have to be okay about it yourself, otherwise you run the risk of damaging a child's self-esteem and they may not recover from that.

More importantly than the words themselves, it's the tone that you take that your child will absorb.

**'Being autistic, I can do everything that other people do - and more!'**

- Bobby Elley  
Age 10



## Cygnets Health Care

Autism and Asperger's Syndrome Services



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

**OUTREACH SUPPORT:**  
For individuals aged 5-64.

**FULL TIME AND SHORT BREAK RESIDENTIAL SERVICES:**  
For young people aged 5-17.

**PARENT SUPPORT FORUMS:**  
Providing advice, resources and the chance to meet other parents/carers.

CYGNET'S OTHER AUTISM SERVICES INCLUDE:

**Springside South West, Exeter:** Outreach support services.

**The Springs Community, Kent:** Residential care for individuals aged 16-64.

**The Springs Unit, Harrow:** Secure inpatient care for adult males with autism & Asperger's.

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

For more information contact Saskia Little, Administrator  
Tel: 0161 443 4060 Email: [peterlawson@cygnethealth.co.uk](mailto:peterlawson@cygnethealth.co.uk)

In AuKids, we refer to ASC or Autism Spectrum Conditions, which is our preferred term. Some contributors refer to it as ASD (Autism Spectrum Disorders) but they both mean the same thing.





Every human being is different, and sometimes, when there are enough differences, it's called autism.

- Alis Rowe, aka The Girl with the Curly Hair  
thegirlwiththecurlyhair.co.uk



### Luke Beardon

BA (Hons) PG Cert (Autism)

Luke is a senior lecturer in autism at The Autism Centre, Sheffield Hallam University, speaker and author.

As is so often the case in the autism world there is no simple 'one size fits all' answer to this issue - and yet it is such an important one! I tend to suggest that there are three aspects that need consideration which will help decide the 'when' of broaching the subject and these are:

1. Intellectual ability
2. Cognitive and communicative ability
3. Motivation

Simply put, unless the individual has sufficient skills in the first two and a certain level in the third, it is unlikely that any discussion will be beneficial. However, with the right mix of these three, I would think that you are good to go.

It is always a good idea to think long term - so, from the earliest possible age, start to identify concepts such as 'difference'. This can be a daily game (is there a difference between an apple and an orange? etc.) and should always be based on the philosophy that a) yes, the world is full of difference but b) being different is not a bad thing. In a similar vein, diversity and individuality can be notions that are developed in a simple, but positive

manner. Then, when it is crunch time, the individual should have an array of ideas and terms than are actually applicable, as opposed to a confusing new set of communications that may muddy the waters.

The individual may also 'tell' you when s/he is ready. Questions such as 'why can't I do that as well as her?' or any questions relating to difference are indicators that the individual may well benefit from having a better understanding of self.

I am beginning to reject the term 'diagnosis' - one gets diagnosed when there is something wrong with you in medical terms, and this should not be applied to autism. I far prefer the term 'identification' and the connotation of 'identity' - to discover that one has a new identity that explains so much can be a wonderful thing - as opposed to the doom and gloom so often associated with a diagnosis. So, please be careful how you choose the terms you use, as the longer term impact can be considerable. If it is feasible, bring the individual's interest into the equation - there are many famous real life and fictional autistic people that you can refer to if applicable.

As much as possible make the news positive - this is an explanation of who a person is, not a dire foreboding of dreadful times to come! However, do also be honest, as the individual is likely to store what has been said and revisit it often. Make the person feel exactly as they should - i.e. as a wonderful, interesting, different to the majority, unique person who has a fantastically interesting brain, and whose future could be anything they choose. Being autistic does not preclude anything at all, apart from not being autistic!



### Tamar Levi

Co-author and Illustrator of My Autism Book: A Child's Guide to their Autism Spectrum Diagnosis

You are not alone. When consultant child and adolescent psychiatrist Dr Glòria Durà-Vilà told me that some parents in her clinic are nervous about discussing an autism spectrum condition (ASC) diagnosis, I suggested we write a picture book that explains what it means in a clear and positive way.

You are the experts of your own child, and you know when your child is most relaxed, so it's best if you tell them about their autism yourself; you can provide a loving and safe space to deliver this message. We wrote My Autism Book to help open the discussion about what a diagnosis is so that you can have those conversations at home.

Choose a time when your child is at their most calm and receptive. Pick a space with few distractions. In our book, we made sure to talk about 'strengths' and 'difficulties' not pros and cons or troubles

and strifes! By communicating the diagnosis positively, your child can understand what it means to them.

Return to any questions your child may have already asked while they were being assessed and use those as cues to start the conversation.

Make sure any information you give them is right for their age. My Autism Book is for ages five and up, but one size doesn't fit all. If a child's ability to communicate is significantly impaired it may be helpful to share the book with teachers, carers and anyone who could support the process of communicating with your child.

When designing this book, I used Crayola™ markers so that the book's images feel hand-crafted and familiar. I drew pictures that show how the world looks from the child's point of view so they can identify and learn about autism from their own perspective. I avoided using facial expressions, as these are often confusing to children with autism. I also included a page where your child can do their own drawing, so that they feel as if they own the book and that their understanding of themselves still belongs to them.

The book doesn't have to be read all at once and can be revisited at any time.

Most importantly, remember, you are going to be wonderful parents of this amazing child with ASC.

## COMPETITION

WIN a copy of **My Autism Book: A Child's Guide to their Autism Spectrum Diagnosis** by Glòria Durà-Vilà and Tamar Levi. AuKids has copies of the book to give away to **THREE** lucky winners. This beautifully illustrated picture book helps parents to explain autism to their child in a sensitive, positive and accurate way using clear language that speaks directly to the child. Published by Jessica Kingsley and usually retails at £9.99.



new!

### Q: At which university is Gloria Dura-Vila an honorary lecturer?

You'll find the answer in the description of the book at Jessica Kingsley's website [www.jkp.com](http://www.jkp.com) Send your answers to AuKids at the usual address or to [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com) with 'Autism Book' in the subject header. Winners will be chosen at random after the closing date of May 31<sup>st</sup> 2014.



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

# COLOUR CODING

The Guaranteed Connection

AS if it wasn't quite enough for teacher Adele Devine to launch her own (now award-winning) company developing CD-ROM games for special needs children, her latest project is an in-depth investigation into the benefits of colour for kids on the spectrum. We caught up with her to find out what inspired her first book, *Colour Coding for Learners with Autism*.

By Debby Elley



Adele Devine

The founder of I.T. games company SEN Assist, a special needs teacher with ten years' experience working with autistic children, laughs when I ask her what inspired her to pile on even more work by publishing a book. "One of my appraisal targets the year before last was to investigate colour codes. Erm, I just took it a bit far!"

Her boundless energy and a penchant for finding creative ways around familiar problems has benefited Adele's pupils for years. Happily, having taken her colour-coding techniques as far as her class at Portesbery School in Camberley (a school for children with severe learning disabilities), she has become determined to share her techniques with other teachers and parents. The result is no small project; an eighteen-chapter

examination of colour, exploring how it can enhance learning.

The author says: "Colour-coding isn't a new therapy. We use colour all the time in special schools to help our children. Showing a 'red' symbol and asking them to go and sit at the 'red' table requires them to process a lot less language. My classroom has a red door, all my kids have red home school diaries and I have a large red diary! When they go to assembly, my class sit on a red bench. The school is already very much into this way of thinking".

Despite the existing prevalence of colour-coding techniques in her school, Adele became convinced that it could be taken to new levels. "I started thinking about the child's day and comparing it to a train journey using an underground map of London," she says.

"Imagine you're in London and going to take the Tube. You get there and it's jam-packed - that feeling you have before you get on the Tube, that you don't want to do it, is like sensory overload.

"You'll measure whether you get on it by how long the journey is going to be and whether you can cope with it, plus the destination at the other end.

"For a child with autism, intensify what you would feel by about six million - the touch, the smells, the feeling of the floor vibrating, visual distortion..."

"The child looks at the timetable in the same way as you'd look at the underground map. How many stops are there? How long is there between each stop?"

For us, the solutions to information overload come in the form of colour. Adele explains: "I thought, when we're on that train, what do we do? We immediately look for that coloured line on the Tube map to tell us about the stops. Without that information, if the doors opened and you saw an escape route, you'd get off. It's that whole fight or flight response". "If the Tube map didn't have those colour codes, it would be a blur of information that we would be unable to process.

direction. The gaps between stops shows us how long to expect between them and we count them down to our destination."

It occurred to Adele that a class timetable could be treated in a similar way. She started by categorising information by colour. The timetable activities were given a purple outline. The 'Now and Next' board - which breaks this down in finer detail for a child, was also in purple, so that they could relate it to the timetable on the wall. Individual schedules, transition boards and anything else that related to the timetable had a purple outline so they could make an easy connection.

Adele then expanded the idea to create other categories. Personal care symbols were all on aqua, partly because the school's bathrooms were the same colour. "They would probably think, this is one of those things that I don't want to do and I'm worried about, but they're going to keep on at me about doing because it's to do with hygiene and personal care!" says Adele.

The idea of colour-coding can be used for all special needs children, but is particularly useful for autistic kids who often have difficulty with central coherence. Whilst the rest of us tend to automatically categorise what we see to make sense of it, the autistic brain struggles to generalise in the same way.

“ .....

**The idea of colour-coding can be used for all special needs children, but is particularly useful for autistic kids who often have difficulty with central coherence**

” .....

"We find which colour we're looking for which shows us which line to follow. When we get on the train, we look for the line of the right colour to check we're going in the right

Before



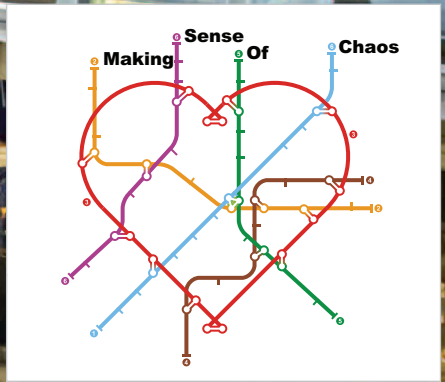
After







To our little commuters,  
every day seems like this  
So maybe we need to try  
something like this



The advantage to this is being able to see things in minute detail that others may miss, and also make creative links between ideas that may not occur to others. The disadvantage is slower processing of information and faster overload. Adele explains that the use of colours can speed up a child's ability to process information.

"This is giving them that stepping stone for generalising," says Adele. "It's all about sorting visual clutter. Because we show them so many symbols, it just gives them an immediate way of knowing what we're talking about. So rather than just thinking 'Why are you randomly wanting to cut my nails?' the kids can see that there's a connection there and they can see that I'm going to keep on at them about this because it's self-care!"

Behaviour symbols were outlined in orange. "They know then that if they do it, that's one of those things that they're going to get praised for. Things like sharing, tidying up the toys, standing in line – anything like that. Any token boards that are linked with good behaviour have an orange outline".

Sport went onto green and food – another big issue for a lot of autistic children – went onto beige.

"The reason for that was that with so many children with autism, their diet starts off with bread rolls or Cheerios – anything brown. Even the more verbal children say 'I eat things that are brown' – they will actually tell you that they've made that decision.

"Outlining everything with that colour, you're saying 'Okay, the food is green but I'm giving you a connection'. As they build the category up, they've got foods that

they've tried and liked, food that they've tried and didn't like and all the other foods – but they're connected and can actually see that all those things are food and there's a relationship between them".

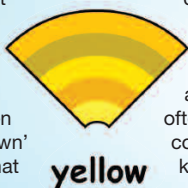
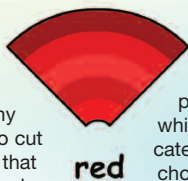
Adele says that colour-coding is great for home use because it's easy for anyone to implement.

To make it even easier, a CD-ROM at the back of the book features hundreds of symbols to download and print. They can be printed off either in black and white or using the colour categories that Adele has chosen.

There is also the option to download symbols of different shapes. "The behaviour symbols can be printed on a thumbs-up outline – why do all the symbols have to be square? The personal care symbols are all on vest shapes and there's a little schedule board you can put them on which is a washing line. It just helps by giving yet another clue as to the symbol's purpose."

The book also recommends new ideas about teaching children how to identify colour. "I investigated how children learn colours, as they are one of the most difficult things to teach. They'll get the concept and sort by colour, but quite often if you ask them what the colour's called they won't know.

Looking at the current symbols in use for colour, Adele felt they were confusing for a literal mind. A generalised red colour on a symbol often didn't match the type of red that was being referred to.



"I redeveloped the colour symbol so that they show a gradient of different reds, almost like a paint chart".

Adele has also created new images to symbolise sand timers, which she uses to denote the amount of time to be spent on a subject in the timetable.

"All of our egg timers are in different colours. The orange one is a ten-minute timer; for my literacy lesson I show three symbols of orange egg timers so that they know how much time they can expect to spend on it. It helps them with the concept of time.

"My reflection at the end of the day lasts for ten minutes. Instead of thinking, 'Oh, I'm going to be here for another hour,' they can see from the timer symbol that it's just a short time. Also if we're going on an outing, I can show them that this takes up a longer part of the day".

I can see how this would reduce anxiety and tantrums and make life a lot less stressful for children, but Adele has thought of coding techniques that are helpful for carers, too.

One ingeniously simple example is a traffic light system to instantly indicate a child's level of independence. "The children have a tag on their bag. If they're on red, they need you to take their hand and take them to the classroom – if they're on green, you let them go on their own and if they're on amber, you watch them. The same with dinner time, rather than explain every single time what they can do for themselves, an assistant will just see that they're on green. It reduces the need for lots of language and it prevents new assistants from giving them more help than they need."

Adele hopes that her techniques will provide an easy aid for anyone working or living with autism, from beginners to experienced practitioners. "In this book I've put together everything that I think will help as a starting point. For a parent who may not even have a diagnosis yet but knows that their child has autism, it's just something that they can easily use".

**WIN**  
a copy of Adele's book, worth £24.98!

**Colour Coding for Learners with Autism: A Practical Resource Book**  
By Adele Devine  
ISBN: 978184905441

Three lucky AuKids readers can win a copy of Adele's new book, Colour Coding for Learners with Autism: A Practical Resource Book. Simply visit [www.senassist.com](http://www.senassist.com) and tell us the names of the six fairy tales that Adele has developed into special needs CD-ROM games. Send your answers to [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com) or AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE, no later than May 31<sup>st</sup>. If you are entering online, put **Colour Coding** in the subject header.

*Good luck!*

Winners will be contacted directly by Jessica Kingsley Publishers.



# Let's Talk!



### Tips for Professionals

- Parents have never been through this before. This has not yet become a normal part of their lives. Never forget it.
- Talk as a co-professional – the parent is an expert in their child.
- Make sure that the parent leaves with some sort of action plan.
- Be open when you are unsure how to proceed and tell them who you are going to contact or what information you'll seek out on their behalf.

**AuKids magazine is a result of collaboration between a parent of twins with autism (Debby) and a specialist speech and language therapist (Tori). Through the years we've seen many great examples of teamwork like ours between parents and professionals. We've also watched from both sides of the fence as misunderstandings occur that could easily be ironed out with a bit of honest dialogue.**

**So in the interests of getting two sides of the story, we spoke to parents and professionals about a range of issues. Let the dialogue begin!**

sometimes overflows into your first appointment with a professional.

Join a support group or internet forum to help you come to terms with diagnosis and seek the help of other positive parents. You can also chat to other parents in your area through AuKids' website, where subscribers can contact each other safely.

also need to underline how easily these techniques can work without needing extra time or resources; they can simply fit into the daily routine.

**Parent concern:** "I haven't even got over this news yet - and now I'm expected to talk about the nuts and bolts of autism."

**Helen Pearson, speech and language therapist, says:** "For many families, those first few days, weeks and even

months after receiving a diagnosis is like being on a roller coaster. Things can move along quite fast, with other professionals becoming involved and family and friends expecting you to know the answers to their well-meaning questions.

"For some, it is a relief to have your thoughts about your child finally confirmed and you may be ready to tackle the 'nuts and bolts' of autism head on. For others, it can be a shock which can impact on all members of the family.

"I work with families pre and post diagnosis and will try to match my pace and style of input to meet not only the needs of the child, but also their parents. My advice is to be honest with professionals and say if you are feeling overwhelmed and unable to cope with too much too soon. Nuts and bolts are important but only effective if the family are emotionally ready to start building them into their lives".

**AuKids take on it:** Initial referrals happen after diagnosis, often with no counselling or support in between. It's not surprising then, that all that pent up emotion

**Parent concern:** "He's not got any words yet. They're not doing their job. I don't get enough speech therapy."

**AuKids' take on it:** Underneath the anger, the emotions are fear and concern. Speech therapists can't make a person talk, however many sessions take place. 'The more the merrier' is a myth with speech therapy. What matters is that the speech therapist transfers those strategies relevant to your child to you as the parent so that they can be practised regularly in familiar settings. Children learn far better from their own parents in a natural way than they do from professionals.

The professional needs to reassure parents that communication and language skills take time to develop and can't happen overnight. They

**Tori Houghton, speech and language therapist, says:** "Be open about your emotions. Tell a professional if something is making you feel particularly worried. 'I'm feeling really anxious that he's not got any words yet,' rather than 'He should be doing better!'"

**Parent concern:** "Why aren't you showing my child how to pronounce words?"

**Helen Pearson, speech and language therapist, says:** "If you talk to parents of young children about their child's milestones, the vast majority will first tell you when their child walked, quickly followed by what and when their child's first word was. For most children, talking appears to 'just happen naturally' and it can be frustrating and upsetting when your child is not following the norm."

### Tips for Parents

- Try to be realistic about your expectations and don't expect overnight change.
- Understand the profession that you're dealing with and what they can do for you. If you're not sure, ask what you can expect from this sort of intervention.
- Communicate your key concern before the meeting if possible.
- Don't be afraid to ask them to write things down.



"We are communicating better but we are still not out of the woods."

"Parents often need reassurance that, whilst the number of words a child says is important, for children with ASC (Autism Spectrum Conditions), it is often not the most important aspect. As a professional, I will be focusing much more on how a child is communicating with those around him/her - through sounds, gestures, facial expressions, body language, eye gaze etc. Therapy, particularly in the early stages, will often focus much more on these 'non-talking' ways of communicating to help a child's interaction with the world around them be as positive and successful as possible".

**AuKids take on it:** Parents need to understand, and professionals need to take time to explain, the range of techniques at a speech and language therapist's disposal. Autism isn't about a lack of ability or willingness to pronounce words, it's about the motivation to communicate. Speech therapy techniques that tackle this motivation are often very successful in the long run, but can at first seem quite alien to parents who have only heard of speech therapy being used to 'solve' stutters and lips and 'create' language where no understandable language exists.

**Parent concern:** "I've been waiting ages for an appointment, then I sit there and I feel like a rabbit in headlights."

**AuKids take on it:** Our advice is to prepare beforehand. Gather evidence on behaviour that causes you concern, charting examples and strategies you've tried. If possible get a letter from a nursery, school or other agencies who have witnessed this behaviour as they'll no doubt have a slightly different experience of it.

Prioritise the things that worry you according to how much disruption to your life and to your child's life they are causing.

Don't be afraid to pull out notes in front of a professional. This isn't a memory test.

**Tori Houghton says:** "Don't be intimidated by a professional. Their understanding of autism may sound very technical but they're very used to hearing about daily issues. Be realistic about what an appointment can achieve. Focus on your main concerns".

**Breanne Black, Independent Occupational Therapist, says:** "I have found that parents are often pretty desperate for help and by the time they get to an Occupational Therapist, what started out as irritating behaviours

can sometimes have become established behaviours in which careful analysis and time is required. Parents are so relieved to be through the door that you often get ambushed with everything that is a challenge at that time.

"It would be useful for parents to note the emergence of specific behaviours or concerns in a shortlist prior to the appointment. Then the professional can look through the list and help parents to focus upon areas in which their specialism can help, in addition to signposting them elsewhere when concerns aren't best served by them.

"Parents should feel able to contact the OT (Occupational Therapist) over the phone before an appointment if they need any guidance regarding this pre-visit list. This can ensure they get the best from that appointment. They may have been waiting a long time, so best to use it to its max!"

**Parent concern:** "Things are bad but I'm used to putting a brave face on it. I don't really want to admit it."

**Tori Houghton says:** "Don't be afraid to open up about strange behaviour - they have heard it before. Now is the time to be really honest, because professionals don't have enough time to read between the lines. And believe me, professionals WILL still believe you if your child is good as gold on the day and not exhibiting the behaviour you're describing. We do understand that we only see a snapshot of your child".

**Parents should be quite assertive - you are the expert in your own child, whatever autism knowledge the professional may have.**

**Heather MacKenzie, speech and language pathologist, says:** "One of my concerns is parents who are reluctant to tell others that their child sometimes explodes and strikes them. These episodes are treated almost as 'dirty little secrets' that, if others knew about, would reflect badly in some way on their ability to parent their child and/or would reflect poorly on their child. Parents need to understand that these episodes can be part of having a child with autism and professionals can help. Of course, the parents must be able to



## Things have changed a bit since 1975. So have we.

But our children and young people's services have always been about what's best for them. Providing the right place and the right support to succeed in achieving the best outcomes, even in the most challenging circumstances.

Our schools and colleges offer specialist, flexible education and care for young people, all of whom have complex needs including behaviour that may challenge and a learning disability, often in association with autism.

Visit our website [www.hesleygroup.co.uk](http://www.hesleygroup.co.uk) to find out more about our services for young people or call us on Freephone 0800 055 6789.



Established in 1975, Hesley Group, through its schools and colleges support 8 to 25 year olds with a highly experienced and expert multidisciplinary educational, care and therapeutic staff resource, in high quality purpose built settings. We're focused on positive outcomes and progress towards sustainable independence.



trust that the professional will understand this. The professional needs to earn that trust".

**Parent concern:** "I guess they know more about autism than I do, so I'll just shut up and listen."

**AuKids take on it:** After diagnosis, you're on the back foot as a parent. You've been told something new about your child that may be very unfamiliar to you. So you're pretty vulnerable in that respect, and when a confident professional makes sweeping claims, you may not feel able to dispute them.

Just be aware of two things. Firstly, a professional who is worth their salt will always listen to your own experiences of your child first and foremost, rather than talk about autism in general. Secondly, your gut instinct is a very powerful steer and you should feel able to pipe up if you feel that what they are saying doesn't describe what you're seeing. If a professional really won't listen to you, you should try and get an alternative referral.

**Dr Heather MacKenzie says:** "Unfortunately, there are professionals who will make you feel as if you know less about your own child than they do - the professionals who assess a child and pronounce what they can and cannot do, some

of which is at variance with what the family observes.

"Both the parents and professionals must accept that the child's performance varies by context, materials used, people interacting with the child, and so on. The variances should be discussed calmly and rationally by the professional and parents, trying to tease out what the child can actually do and what the main variables may be. Parents should be quite assertive here - you are the expert in your own child, whatever autism knowledge the professional may have."

**Parent concern:** "I don't like talking about my child in a negative way whilst they're in the room."

**AuKids take on it:** It's a good idea to bring someone with you who can play with your child in the waiting room whilst you chat about concerns. That way the professional can still observe the child first.

**Dr Heather MacKenzie:** "Children with autism are highly sensitive to feelings, emotions and attitudes around them. Concerns about the child should be discussed in private between the child and a person they trust and not in front of them."



# THE TEN COMMANDMENTS OF BRINGING UP A CHILD WITH AUTISM

Ten years' worth of blunders and blessings have led me to a place from which I can look back and view the positive turning points of my life with twins on opposite ends of the autism spectrum. Here I've condensed them into ten messages which with any luck will speed up the learning curve for someone who has yet to climb the same mountain! This is also available as a talk – see end for details.

By Debby Elley



## 1 THOU SHALT KEEP POSITIVE

Keep positive! But what does it mean and how do you do it? The practical advantage of keeping positive is that you become much more efficient at problem solving. You quickly move from recognising a problem to seeking practical solutions that will nip them in the bud. Use your worries to propel you towards practical action. If you hit a brick wall trying to find a solution, back up and try a different route. Someone has been here before you, and thought of an answer. So network to find a solution.

When the twins were young I avoided negative people like the plague. You really don't need other people's often unrealistic anxieties washing over you like toxic waste. It saps your energy. I learnt to see my energy as a positive powerful force, and I guarded it closely.

There really is no mystery to being positive. Happiness comes when something exceeds your expectations. Unhappiness comes when something fails to meet your expectations. If your expectations are constantly very high and your child fails to meet them, you will be unhappy. More to the point, so will they, since even pre-verbal children with autism are very sensitive to a 'vibe'.

I learnt to look at the twins' development through a magnifying glass, seeking out small but significant changes (with the help of professionals like Tori) and focusing on what they could do rather than what they couldn't. Looking for small changes rather than expecting big steps lead to my expectations being met and exceeded more often.

Why are some people so happy in life? It isn't because they are more lucky than you or I, or richer. It's purely down to perspective. That puts you in a powerful position. Choose to see autism as a different way of being rather than a disability – with advantages, not just 'impairments'. Choose to recognise tiny steps forward.

## 2 THOU SHALT NOT BE TOO PROUD

I was plain stupid until the kids were four years old. 'I'm their mum, I can cope, I'm superwoman'. Of course you can cope. The question is – at what cost? This is a marathon, not a sprint folks. The biggest misconception that I suffered was that help was only available to those poor souls about to crumble and that I had no right to deprive them of it by taking it up myself. Help is designed to reach people BEFORE they get to a point where they crumble.

Don't grasp your child tightly to your bosom thinking: 'No one else will understand them like I can!' You'd be surprised. You just need to choose people who understand autism and have the willingness to get to know an individual well. It does them good as well as you.



## 3 THOU SHALT KEEP CALM

Those of you who've been with us for a while will remember that we thought being calm was so important that we dedicated an entire issue to it.

The more calm you are, the more calm your kids become. The more you practise being calm, the better you get at it. For me this means being acutely aware of the volume of my voice no matter what the provocation and however I am feeling inside. I do shout, but it happens when the kids are genuinely being naughty and not just when I'm frustrated and need to vent.

Learning patience and tolerance has improved every aspect of my life. Helping your kids to recognise what keeps them calm is very important, too.

## 4 THOU SHALT SEE THE WORLD FROM THEIR VIEWPOINT

When our family went to see some air raid shelters, Bobby filmed the entire thing on his camera. Looking at the film, it struck me that his experience of the visit was totally different to ours on account of the fact that he is half my size. Added to that, his autism would have made the experience different in two major ways.

Firstly, whereas we have an organised folder system in our brains that allows us to categorise every new thing we come across, for him this doesn't work quite so efficiently. This means that he focuses on detail more, without looking at how that fits into the bigger picture. This observation can sometimes work to an autistic person's advantage and lead to great creativity, but it can also lead to overload.

Bobby's brain is more likely to make links with something recent that he's really into – a whole load of seeming drivel will follow whilst he categorises the unfamiliar according to the world of Sonic, Mario and Raving Furbies.

The second thing that will drive Bobby to behave differently is how his senses process the new surroundings. Sensitivity to sound meant that anxiety over the bombing noises during the wartime showreel stopped him from learning altogether.

If you can't see the world from their viewpoint, it becomes hard to help your child. Fortunately we are living at a time where much is written about sensory integration, some of it mentioned in this issue – and autism is becoming more understood.



### 5 THOU SHALT ENJOY THE PRESENT - IT'S A GIFT

One thing used to mar my early years with the boys, particularly with Alec, was that I felt the need to be his therapist. Any time that I didn't spend helping him to be productive, I felt guilty about. I spent a lot of time trying to help him draw when he just wasn't interested or motivated.

It was only a lot later when I realised that the best therapy of all is having a laugh with your child and mucking around with them. This builds a bond and makes them receptive and confident. And I've now become more adept at building therapy into fun time without making it into a big deal that is a chore for me and for Alec.



### 6 THOU SHALT AVOID COMPARISONS

Neurotypical children are apples, and I have two pears. If you are comparing your pear to apples all the time, it will make you unhappy. I learnt to only compare Bobby and Alec with themselves. Each one of us is on our own journey in life and the only measure of progress should be against yourself.



### 7 THOU SHALT TRUST INSTINCT

Is instinct just a hunch? No, it's actually reasoned judgement, it's just working at a speed too fast for us to comprehend, taking into account many more variables than we could possibly process at a conscious level.

When we're given a diagnosis it can make us question our own natural instincts as parents. But I've learnt that instinct is more powerful and accurate than all the medical knowledge in the universe.



### 8 THOU SHALT ACT EARLY

Finding the energy in the early years to iron out small behavioural difficulties was tough, but boy was it worth it. It started with cartoons after an incident to help Bobby understand how he was thinking and feeling. I learnt to focus on that, rather than telling him off for bad behaviour. Usually he knew only too well that he'd been out of control and liked it even less than we did.

It meant sitting down in the calm after the storm and analysing together what could have gone better next time. It meant listening to his thoughts, recognising and respecting them - and calming myself when I felt like kicking the front door down! It meant helping him to understand the physical and mental signs of frustration and what he could do about them.

I didn't always do it perfectly, in fact I didn't always do it full stop, but I did it enough of the time that it made a difference.



### 9 THOU SHALT NEVER SAY NEVER

We sometimes think that in order to protect ourselves from disappointment, we need to believe that the worst will happen. The problem with this is that it can become a self-fulfilling prophecy. If you don't truly believe that your child will do something, you communicate that in all your efforts, and hey presto you end up getting what you expected.

Plug away and have faith, even if it takes months or years. There is no deadline to development. As famous speaker Ros Blackburn's mother told her:

*'There is no such thing as cannot. There is can, but not yet.'*

It's one of my favourite quotes.



### 10 CHAMPION THY OFFSPRING

Imagine your best buddy. Now imagine that before meeting them, someone had told you that they could be really difficult to deal with. Imagine how that would taint your perception of them, even if you witnessed no evidence of it yourself. You'd even end up looking for it.

Sometimes we worry whether others will be able to cope with our kids, so we shovel all the negative information their way the minute they meet junior.

Use some psychology when dealing with people who are about to look after your child. Introduce your child with a massive grin on your face and tell them how they're going to love them! Are they a great giggle? What gets the biggest laugh out of them? People who champion your child need to see what you see in them. Then they can take that baton forward and communicate the same message to those around them.

Sure, tell them the challenges, but don't let them be the first thing that you mention.

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### EXTRA INFORMATION

- If you want to learn more about staying calm, look up Issue 14 - available for subscribers to download online via our magazine archive at [www.aukids.co.uk](http://www.aukids.co.uk)
- The Ten Commandments is available as a talk to support groups to raise funds for the magazine. If you are interested, contact Debby at [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com)

# Sunny Side Up

It may only be May but within two months you'll be looking at that calendar thinking ARRRRGGGGHHH. And as Jason Donovan, that lyrical genius, once said: 'Fail to prepare, and prepare to fail.' Here's our top tips to help you keep your head above the water all summer.

## Indoor Ideas

Since it can be tricky to play with autistic kids, it's tempting to take them out daily to fill the time. But they need time alone and constant stimulation can be stressful. Instead, try the book *Motivate to Communicate* by Simone Griffin and Dianne Sandler (Jessica Kingsley) to help you with some great and easy ideas at home.

## Gambol in the Garden

If you're out and about, kids are bombarded by new sensory experiences constantly. Don't underestimate the garden, instead of the park. The hose, a ball pool, chalk, a sandpit and bubbles are all good motor exploration – just don't get too hung up on building stuff.

## Just Say The Word

When outdoors with a pre-verbal child, just supply the simple words and phrases that they would use if they could talk as you watch them play. You don't have to build an Aztec sand temple to make it a worthwhile development activity!

### Power Shower

If your child enjoys a baths or shower, go ahead – have it at the 'wrong' time of day, in a dark bathroom with floating lights. Use bath crayons ([www.elc.co.uk](http://www.elc.co.uk)), water pistols, Gelli Baff ([www.learningshop.co.uk](http://www.learningshop.co.uk)) or foam to make funny hair and share a laugh. Spend the morning there – who cares?!

## A New Leaf

Getting out new books and DVDs each week can provide great novelty value and your trip to the library can form yet another part of a temporary weekly routine.

Check to see whether you can get a special needs library card that waives the price of DVD loans and also overdue book and DVD fees.

## TV times

All kids watch telly. For autistic kids this may represent an escape from other demands and a programme that's familiar creates a predictable routine that they may well need during the unscheduled holidays. If you have set TV and computer times, then your kids will get into a routine they can stick to.

## Schedule in housework

You'd be surprised at how much time this can take up when you intended to sit and play together. But don't schedule it in for the evening – that's obligatory feet up time!

Plan plan plan!  
Make sure you're first on the list for activities going on....Speak to friends and relatives to arrange days at each other's houses. Make sure they know that only a death will be accepted as a reasonable excuse for dropping out on you!

- Sue, reader

## Save A Trip

Doctor's prescriptions can be sent directly to the chemist; yes, that's for people like you! Do your supermarket shop online, too.

## Tailor the time

Ask places what their quietest times are. An early or late hour in the park can be much easier and more relaxing than at peak times.

## Make it AM or PM

Decide either a morning trip or an afternoon trip unless you have help – days out can be exhausting to plan and pack for.

## Plan Ahead

The more planning you do, the less anxious they'll become. Plan WITH your child the activities they are going to do (even the indoor ones) and produce your own little timetable as a holiday schedule.

Always have a back-up plan, my handbag always has a DS in it and our son's MP3 player. When difficult moments arise, just 5 mins on the DS can bring him back. Offer lots of praise and rewards, not just bought items as reward sometimes

- Zena, reader

## Ticked Off?

Mark novel trips out and visits to other people's homes on the calendar.

Some kids love a foot massage to help calm them and it will relax you too!

## Early Bird

In June, start finding out about what's available for autistic children in your area. Family Information Services, if you have them, can be a great source of information. Got a good place or support group you know about? Share it on AuKids Facebook site!

Last year I made a summer holiday calendar with nice big blank squares, which I then laminated. Then as plans were made and sometimes changed, we were able to write it on/wipe off. We took it on our caravan holiday. We also used it to cross off each day as a countdown for back to school.

- Sara, reader

## Picture Perfect

Make sure you have photographs and Social Stories™ available if your child is attending a club or having someone new look after them. You can read how to write a Social Story™ in Issue 15 on our online archive.

Be happy to play Play Doh™ without making anything at all. Roll, prod, cut, squeeze – provide the words as you play. It's still good for development.

## Chill Factor

Have times when you deliberately demand nothing of your child and just keep them company with what they're doing – nothing else.

## On Track

Do they love trains? Buy some new train track to be produced at the start of the summer holiday. Take photos of your best train track effort so that you can reproduce it when tired.

My top tip for summer holidays is, visual timetables! I have pictures to cover everything, pictures of family etc. - it really helps!

- Gina, reader

## Virtual World

Go onto You Tube to look at marble runs, experience roller coaster rides and look at mini train rides from the comfort of your own home.

## Bounce Away Blues

Mini trampolines and giant therapy balls are very good for letting off steam indoors.

Record lots of TV programmes to calm stressful moments. I have also learnt that instead of using respite times to go out, I feel better if I use a lot of it to sleep!

- Amanda, reader

## Want more?

Check out reader Kristina Hughes' guide to her autism friendly summer, ready to read on our Home page now! [www.aukids.co.uk](http://www.aukids.co.uk)

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# The Last Word

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



## The Back Door Method

If I had to sum up the range of techniques that I've used in parenting autistic twins, I'd coin it 'the back door method.'

Most parents use the front door method in order to communicate with their kids. If you think of what it takes to be spontaneous, the back door method is exactly the opposite.

This is the front door method: Want something that's too expensive? No, I'm afraid you can't have it. Don't want to do your homework? Too bad, I'm afraid you have to. Running out of time to get ready for school? Come, on hurry up kid! Got something else planned for the next hour? Turn that thing off, we're going!

Great, isn't it? You say what you mean, when you mean it, in the way that you feel it - and you tend to get a reaction. It may be grudging, but it does the job.

I tried the front door in the twins' early years and I learnt that the more you try it, the less effective you become. If an autistic child receives an instruction without warning and reasons, they blow. Sometimes this is caused by fear and anxiety. Will I be able to do what I'm being asked to do and how long will it take? Will I be comfortable in new surroundings? Will I be ok?

Their response: *If I'm not sure, I'll just say 'no'. Or, even better, I'll scream the place down.*

The back door method (learnt through years of input from experts) can be tiring, but the absence of meltdowns makes it worthwhile.

It's a range of strategies designed to get an autistic child to follow instruction without having the sort of result that would blow the roof off the house. It consists of warnings, visuals, countdowns, explanations and carefully plotted timetables. All of this is designed to take anxiety out of a situation and provide certainty and stability.

So, want something that's too expensive? Yes, you can have it. You can have it when you've saved for it. Here's a chart I've prepared for you. Saving for it will take you 15 weeks. We'll cross it off a week at a time.

Don't want to do your homework? Let's think about how long the homework is going to take you. Now let's see exactly what it is that we've got to do. Shall we decide the time when you DO want to do your homework? And let's make you a Social Story™ about why it's important to do our homework so that what we learn at school stays in our brain for longer.

Running out of time to get ready for school? Well, let's make a little tick off chart with the list of things you have to do to get ready for school. Shall we go through it together and decide how long each job is going to take you and what time you want to do them so that you are ready in time? Let's use your fave Mario and Sonic figures and put some Tom Tag stickers (thanks to Orkid Ideas) on your bag to help you remember the items you're responsible for.

We've got something else planned for the next hour? Well, that's good because an hour ago I set your countdown clock to 60 minutes, drew your attention to it and gave you a photograph of where we'd be going after that. I've stuck the photo on the 'Now and Next' board. So now you're ready.

I'm not suggesting that this will happen for everyone, but a funny thing has happened to us. After years of using the back door, Bobby has begun using the front door, too. Maybe it's because he feels more secure and the trust is there, maybe it's because he's matured. But who knows, one day you may say: 'Put on your shoes, we're going!' and you'll actually do just that!

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