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Quitting the role of butler



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How the best schools beat bullying



From A to Zzzzzzzzzzzzz
Three families who solved sleep issues

PLUS



Temple Grandin, Tony Attwood and Tech Camps reviewed



Letter from the Editors



Happy Birthday AuKids!

Wow, 8 years in publication! So, after all this time – are we still getting it right?

This spring we launched a customer survey and we'd like to share the results with you.

When asked if you would recommend AuKids to a friend, 72% of you said you would. Rating the quality of the magazine, 90% of you rated it as 'very high' or 'high'. 78% of you said that the magazine met your needs either 'extremely' or 'very' well. 80% of you rated the value for money of the magazine as 'excellent' or 'above average'.

We asked you what AuKids did really well. Humour and positivity came out top of the list! You like feeling part of a club and enjoy real life stories from other families. The lack of jargon and waffle was also something you commented on. As well as this, the practical advice and friendly tone was also appreciated.

When asked for improvements, some of you would like us to have more from parents and people on the spectrum. More was requested on girls. Schooling was also a theme. Above all, people want us to write more for teens with autism. Watch this space! One or two of you felt the pages could be rather busy; this is down to us trying to cram as much help as we can into the space, but we'll keep that in mind.

We'd like to thank you all for your highly supportive and positive comments about AuKids. The many messages gave us a real boost!

Enjoy our 8th Anniversary issue! We hope you can see that we've already included some of your suggestions.

Tori & Debby



MINI FAN: Massive congrats to graphic designer Jo and husband Paul on the arrival of baby Lorna in April. Jo says "Last issue was complete just as I was wheeled into the delivery room and this issue has been done during Lorna's naps!"

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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Some of your comments:

It's like a little ray of sunshine landing through the letterbox!

Makes me feel connected with the ASD community. But what it doesn't do is patronise which I love.

The content is exceptional. I subscribe to nearly all of the autism magazines out there and yours is the only one I read from cover to cover!

I look forward to it and enjoy taking time to read it. I love the friendly easy to read feel it has. So informative without being over wordy.

Uses easy to understand English without waffling in a boring, convoluted, and off putting way. Shows real empathy and understanding of issues its readers are facing.

When I was given the magazine at an event I felt very isolated, the magazine was like a friend. I was able to order back copies of the magazine which I keep by my bed, I reread these a lot.

It really speaks to people and is positive and respectful. Your recent piece on girls on the spectrum was great and the book and media reviews are wonderful too.

COMPETITION WINNERS FROM ISSUE 31:

- **I Am Aspiengirl:** Mandy Potts, Southport and Rachel Kaye, Manchester.
- **Neurotribes:** Caroline Wynne, Chester and Antony Morris, Huddersfield.
- **Why Do I Have to?:** Michelle Hayes, Manchester and Judy Newton, Nuneaton.

EDITORS: Debby Elley and Tori Houghton

PRINTING: R and P Printers, Dukinfield

GRAPHIC DESIGN:  periscopestudios

Dan Salmons isn't a professional illustrator. However he is a professional brother (Debby's actually), likes to doodle and is rather good at it, so we let him loose on page 8 and page 16. Hope you like his drawings.

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READERS' PAGE

Send your letters and images to editors@aukids.co.uk

Dear AuKids,

My son was diagnosed with Autism at the age of 5 (he is now 8). He has had a lot of support at home and school and he has learnt to cope with many situations amazingly. As autism parents we have felt a little isolated and lonely so when a friend told me about your magazine I was very keen to sign up to a subscription!



As a 'thank you' for all that you do and the support and encouragement you give to other autism parents I decided I wanted to raise some money for you. My sister and I ran the Great Manchester Run (10K) in 1hr 3mins and raised £355 in donations for AuKids. I managed to knock 10 mins off my first go at it last year so I am well chuffed!

Thank you for being such positive role models and an encouragement to us all!

With love, Sue Green xxx

Dear Sue - We are completely and utterly delighted that you decided to run for AuKids and this is an amazing personal achievement as well as a considerable contribution to the costs of running the magazine. Thank you so much from all of us at AuKids! X

Celebrity SPOTLIGHT

Age: 5 | live: In Heaton Mersey

Diagnosis: Autism

Oliver is a happy boy who is often smiling and has an infectious giggle. Although Oliver understands a lot, he struggles to communicate verbally with others. However, he has a wonderful memory and through word recognition he can read many story books and he can spell all of his favourite programme titles using magnetic letters on his whiteboard, which is pretty amazing!

Likes: Jumping in puddles, bubbles, climbing, bouncing on the trampoline with his sisters, swings, ball pools, slides, swimming, singing nursery rhymes, LEGO™, reading, iPad, scrolling credits, calling out bus numbers, camping, canoeing and throwing stones into water.

Doesn't like: The phone or doorbell ringing. CBeebies on the TV. Any food that isn't fruit, sausages, cheese or bread.

Send your celebrity details to editors@aukids.co.uk



Oliver Billington

I like:
Jumping in puddles

I don't like:
The doorbell ringing

Brendan's Running the Country Er, Literally!

In 2009, our friend Brendan Rendall visited an organisation called Friends of Mulanje Orphans (FOMO), which cares for 4,500 orphaned children in Malawi. He was so inspired by FOMO's work that he decided to support them by raising £35,000 for a science and art extension at a new secondary school there.

Having known AuKids because of his work with autistic kids through our sister company, Time Specialist Support, Brendan decided to help our social enterprise too, by wearing AuKids T-shirts for his biggest

fundraising challenge to date – running the 650-mile length of Malawi.

Brendan's journey started early in July and he is planning to run 26 miles a day for 25 days. He will be camping at schools and it's expected that hundreds of children will join him en route, whilst his team will hand out footballs to schools along the way.

Follow Brendan's incredible adventure on Facebook at www.facebook.com/Helpfomo35/ or on Twitter at #RunMalawi.

You can donate by going to www.justgiving.com/fundraising/helpfomo35

AuKids wishes Brendan the very best of luck and a good physiotherapist!

He's Not Naughty!



A Children's guide to Autism

Reader Deborah Brownson, author of He's Not Naughty! is running a campaign for compulsory autism modules on teacher training courses. This initiative has taken her to 10 Downing Street and Westminster, where the issue was discussed with the Minister of State for Children and Families.

On May 9th 2016, the Director of Special Needs for the Department of Education confirmed at a meeting of AAPGA (the All Party Parliamentary Group on Autism) that the Government is looking to make autism a compulsory element on initial teacher training during academic year 2017/18.

In the meantime, Deborah has started a drive to provide an ebook version of He's Not Naughty! A Children's Guide to Autism, free to all schools in the UK.

Deborah says: "This book can help train all school staff quickly and

easily and also help explain to classmates in a highly visual and fun way, why children with autism behave the way they do, which hopefully will reduce bullying. I won't benefit financially at all from this, but a lot of children with autism will!"

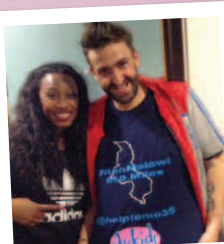
E-book copies of He's Not Naughty! have already been provided to all primary schools in Barrow, Cumbria.

Deborah says: "I'm working with my MP John Woodcock and Cheryl Gillan MP, Chair of APPGA, to give a free copy of my e-book to all schools in the UK and met with Carol Povey from the National Autistic Society to ask for their help in achieving this".

Deborah has created a short film with the BBC on her campaign, which you can see here: www.bbc.co.uk/iplayer/episode/b06kjp86/inside-out-north-west-26102015

She is also working with BAE Systems to make the company more autism aware and to help to adapt their recruitment practices in relation to autistic people.

To find out more and to buy the book, go to www.hesnotnaughty.co.uk



Singer Beverley Knight is one of the high-profile stars supporting Brendan's quest.

The first AuKids logo in Malawi as Brendan arrives for his big charitable run!



Reviews & Prizes

Oojamabobs Have The Fiddle Factor

Sensory Oojamabobs (www.sensoryoojamabobs.co.uk) is a small UK company producing funky, chewy jewellery for those with sensory needs and those who just like to chew!

With a wide range of affordable pendants in many different colours, each item can be customised by choosing from over 80 different lanyard designs. Whatever your kids' special interest, there is bound to be a lanyard ribbon to suit – everything from Thomas the Tank Engine, to Pacman and Minecraft is available!

Sensory Oojamabobs also sell Fidgi-Flips! These are an innovative metal fiddle toy which is also widely customisable, available only from Sensory Oojamabobs.



WIN an Oojamabob!

To win either a chewy pendant or a Fidgi-Flip in your choice of colour and lanyard design, just find where the 'Ooj' logo is hidden in the magazine. Send your answer, together with your name and address and prize choice, to us at competitions@aukids.co.uk with 'Oojamabob' in the subject header. Or you can write to AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE. Competition closes August 31st 2016.

Good luck!



BOB'S YOUR UNCLE - 10% OFF!

AuKids readers get a lovely 10% discount on all things Oojamabob by using AUKIDS16 as a promotional code until October 31st 2016.



TALK

A Day with Temple Grandin Town Hall, Reading June 2016

Hosted by the National Autistic Society

◀ IN THE FRAME: Our friend Abbi from Oojamabobs gets photographed with Temple at the NAS event

So, you may ask: What IS the big deal about Temple Grandin?

Since the publication of 'Emergence' in 1986, Temple Grandin has helped to redefine how we think of autism. As noted in the foreword, at the time there was "no other book like it- even remotely like it," as here an adult on the spectrum tells the story of how she grew "from an extremely handicapped child who appeared destined for permanent institutionalization to a vigorous, productive, and respected adult who is a world-authority in her field."

Uniquely for its time, the book provided a detailed insight into what it was actually like to be autistic. Although nowadays we are fortunate enough to have countless other autistic folks writing about their experiences, huge credit must go to Temple for blazing this trail.

Her first speaking appearance at an autism conference in the mid-1980s was another landmark first and her ability to answer questions from parents led to her quickly becoming sought-after.

In 1995, Oliver Sacks' book - An Anthropologist on Mars - named after the chapter about Temple, catapulted her to worldwide fame.

Her next book, Thinking in Pictures, became an immediate bestseller. Since then she has published widely about both autism and her work with animals and is now recognised as a world authority in both fields simultaneously.

She has attracted criticism, especially from other adults on the spectrum, for the way she frames the spectrum as linear with "Einstein types at one end, and at the other end people with a severe disability who can't dress themselves" and has even been accused of 'ableism' by some for her comments in The Way I See it: 'Preventing severe autism would be a worthy goal but preventing mild autism and Asperger's would be a grave mistake'.

This interesting talk was based on her three recent publications: The Autistic Brain, The Way I See It and The Loving Push. Here she focused on the importance of figuring out what kind of thinker a child is and using that knowledge to develop their strengths with a view to using these in a work or volunteer setting.

As author Brenda Smith Myles told AuKids: "She teaches us all that individuals with autism have limitless potential. There is no greater message than that."

By Mark Haworth,
AuKids readers' panel



CONFERENCE

National Autistic Society Conference - Autism and Mental Health Marriott Renaissance Hotel, Manchester

May 2016

In a rare UK appearance, Professor Tony Attwood drew hundreds of professionals, parents and adults on the spectrum to this event. The focus was on presenting the latest research and best practice in diagnosing and supporting mental health issues in children and adults with autism.

His keynote address included a comprehensive list of tools and an explanation of how we should use

different kinds of tools at different points on the 'thermometer' e.g. relaxation tools at low stress levels and physical tools at high stress levels.

This was followed by a plenary talk from bestselling author Luke Jackson, taking a personal look at Asperger Syndrome and Bipolar. He talked very openly about his journey getting to both diagnoses, his many ups and downs and the coping strategies he uses to manage these.

The day then split into three 'streams': clinical, interventions and education. There were two sessions with Tony Attwood which I attended, titled 'The practical applications of recent research in ASD at home and in the classroom' which reviewed some recent journal articles for useful tips and

'Challenges in the diagnosis and treatment of depression in autistic teenagers and adults'.

One great idea in the second of those sessions was 'Energy Accounting'. The concept centres on keeping tabs on your energy levels in exactly the same way as a bank account. In the withdrawal section, you note the activities which deplete your energy while in the deposits, note the activities which refresh your energy levels. You give each activity an energy score; e.g. sometimes, socialising might be a 20 drain and at other times 100. The resulting daily figure gives a measure of your energy and can alert you if you are repeatedly doing activities which sap your energy levels, which could lead to 'energy depression'.

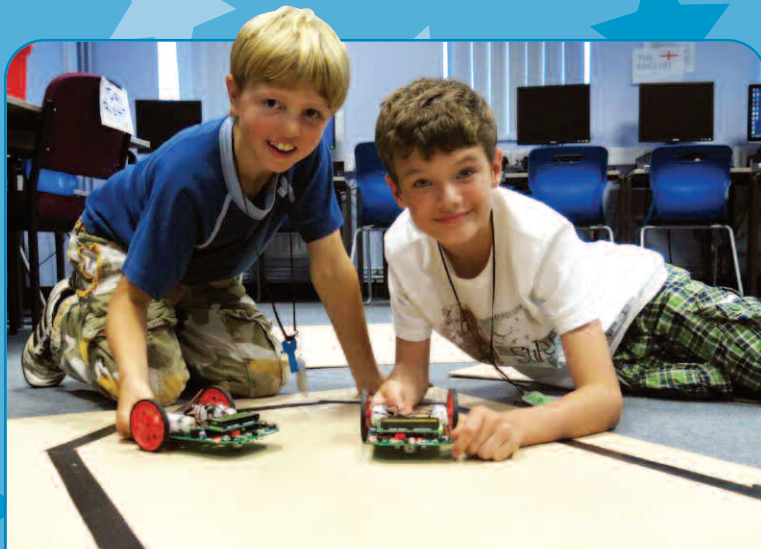
Other sessions covered topics such as catatonia, the use of pharmacological interventions, CBT for women, mentally healthy schools, ASD and OCD, music therapy and anxiety management.

The conference layout could have taken into account the crowds – an adult with autism I know mumbled: "There's too many people..." as we squeezed past each other at a bottleneck. Overall, though, today was very useful.

Attwood's comment: "I think that mental health services don't understand autism," got a spontaneous cheer.

Events like this can hopefully bridge that gap.

By Mark Haworth,
AuKids readers' panel



PREVIEW: TECH CAMP

Who for?

Kids aged between 9-18 who love technology, whether on the spectrum or not.

For day campers:

Four separate weeks in July and August 2016 at Chelsea Academy, London.

For residential campers or day campers:

Run over four weeks in August at The Wessex Conference Centre in Winchester

Tech Camp's mission is to 'inspire tomorrow's inventors', through its coding, electronics and engineering holiday camps and courses. Building robots and rockets, learning coding skills, designing computer games, 3D modelling and electronics are just some of the activities like-minded students enjoy at Tech Camp.

either Winchester (residential) or London (non-residential). Students from across the UK – and from further afield – attend the camps and learn from tutors with bright, young minds and a passion for technology and engineering.

Tutors are carefully selected based on their specific technology-related skills, their love of the Tech industry and their genuine ability to inspire tomorrow's young tech enthusiasts. In fact, some of the tutors are ex-Tech Camp students themselves, who are now studying tech and engineering at the likes of Cambridge and Imperial.

Small tutor groups are maintained – with a maximum of 1:8 staff to student ratio – to provide the best possible experience. On top of this each camp also has a manager – normally an experienced teacher and/or parent to ensure the camp runs smoothly and to look after the welfare of the campers – and depending on the size of the camp, a number of assistants as well.

Tom Ward, Tech Camp's founder and trained as both an electronic engineer and teacher, tells AuKids: "We get quite a few students each year who are on the autistic spectrum and they normally cope really well. A combination of small tutor groups, individual assistance and a shared love of technology creates an inclusive environment where campers are free to be themselves outside of a conventional school environment".

For details of Tech Camp visit www.techcamp.org.uk

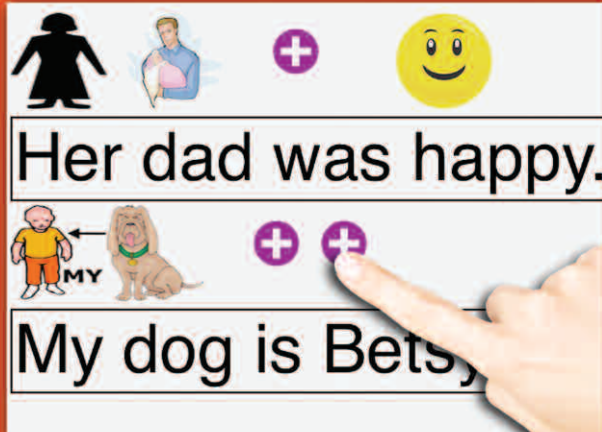
What did the Tech Camp kids think of it? – see our October issue.

All projects involve innovative take-home projects, so the learning and fun can continue at home. Tech Camp's innovative course material has been developed over eight years and is continually refreshed to appeal to both beginners and serious technophiles alike.

Established in 2008, Tech Camp is the UK's original and longest-running provider of these camps, which students can attend in

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AuKids magazine, Summer 2016



“I worry about my son spending too much time doing the same thing again and again. Should I worry? Is it harmful? What can I do?”



Together Trust Together for Families Team

Highly specialist Occupational Therapists, Speech and Language Therapists and a consultant Educational Psychologist work collaboratively to support young people with ASC and their families at home, school and in the community. They provide specialist autism advice and training to professionals in a range of settings.

Left to right: Sue Whitehead (Head of Therapy Services), Steve Tyler (Psychologist), Alison Fielding (Speech and Language Therapist), Mary Sheard (Occupational Therapist)

Mary Sheard, Occupational Therapist:

Temple Grandin (Thinking in Pictures, 2006) describes the repetitive behaviours that supported her to overcome sensory overload when she was a child. She is able to eloquently help us understand the behaviours from her perspective. She describes the detail of contour, shape and colour that she could see in each grain of sand dribbled between her fingers. Consider the sensory experiences of your child, who may gain a much richer understanding from these activities than can be observed by an outsider. Jennifer Cook O’Toole (The Asperkid’s Secret Book of Social Rules, 2013, p228) asserts that she can see “beauty in those pieces and patterns. They’re hypnotic and ordered”. It is important for children with autism to find and use strategies that can support them to feel calm in a world that may feel overwhelming.

Alison Fielding, Speech and Language Therapist:

A routine which seems repetitive to the outsider may be being subtly changed by the child as they build up a new play routine. This enjoyable experience should not be discouraged, but it would be important to try and join their play activity. Perhaps by imitating their actions and trying to establish some joint attention before modelling an extension of their own ideas. This would be a way of joining a child in their world whilst developing an awareness of those around them. Joining their repetitive behaviour can also be a good

opportunity for the child to hear the spoken words that relate to their own actions. Giving a simple, non-directive commentary to describe their actions will help the child build on their understanding of language, by reinforcing key words.

Steve Tyler, Psychologist:

A key point is to try to determine the function or functions that the pattern of behaviour fulfils and the contexts in which it occurs. The same pattern of behaviour may serve different functions on different occasions and in different settings. With a behaviour pattern of this nature, it may be something that occurs when the child is anxious and serve as an emotional regulator. Alternatively, it may occur when the child is bored and seeking stimulation, where it serves as a “low risk” activity that the child has rehearsed before and where the outcome is predictable. Again, it may be an activity that the young person performs for the pleasurable sensation that it provides. In some instances, it may fulfil a number of functions. Once we have determined the function(s) we may seek to provide a substitute and to limit the behaviour pattern to particular times. These times can be put onto a schedule, but the child may be allowed to engage in the behaviour spontaneously if an overriding need is there.

To answer the question, the responses from our team suggests: 1) don’t worry 2) whether it is harmful depends on the patterns of behaviour but in most instances no 3) there are strategies but they may take time to work.

One Person’s Passion, Another’s Poison

Repetitive behaviour may be comforting to one person and troubling to another. Or, more commonly, it can be comforting at certain times and feel like a prison at others.

Co-editor Debby’s son Bobby says he enjoys watching You Tube clips repeatedly because it helps him to remember them by heart. “Then I can remember them when I’m feeling bored. And if I’m upset. Remembering them makes me happy and calms me down”.

But Amanda, an adult with autism who also works with children on the spectrum, has this to say:

“Sometimes I feel compelled to do things even though I may not enjoy the thing. What starts as an interest - in the case of my latest one, *Toddlers and Tiaras* - sometimes turns into an obsessive cycle where every spare moment is filled with the obsession. This would be fine, if the obsession was something I loved (and then I would call it a passion), but when it’s something I never really liked, it’s a completely different story.

“It’s like I’m repetitively doing the thing, wishing the last episode would come, until I can’t do it any more - and then I’m very relieved!

“However, that’s not quite the end of it. When it’s over, I feel like the world as I know it has caved in. Even though I logically know it’s just a TV series (and a really bad one at that), my brain thinks, ‘if that can change, what else in my world can change?’ and I feel this sense of insecurity until a new obsession is found.”



Phoebe Caldwell

Phoebe Caldwell is an expert practitioner in a technique known as Intensive Interaction and has over 40 years' experience working with people whose severe learning disabilities are linked with behavioural distress.

Author of ten books, her latest, 'The Anger Box', published by Pavilion, combines practice with recent neurobiological research.

Autism is a neurobiological developmental disorder. The nerves link up differently. Children and adults on the autistic spectrum experience the world that we share differently from those of us who are not autistic.

Due to problems in their sensory processing systems, they see, hear, feel and generally sense the world differently. This sensory overload is described variously as, 'like being in a kaleidoscope where the pattern never settles', or 'having a lion, or Catherine Wheel, or Molotov cocktail in my head', or 'having my head in a car crusher'. Although the eyes and ears and other sense organs may work perfectly well, messages get scrambled on the way to the brain.

The child focuses on a particular activity to try and cut down incoming sensory overload. This helps them to make sense of their environment - it means there is at least some signal that the brain understands. *When they are doing it, they know what they are doing.* These special activities are known as 'repetitive behaviours' or 'stims'. They are vital for the child to maintain some sense of coherence.

It is very difficult for those of us who are not autistic to take on board what it is like to experience the sensory chaos which may feel life-threatening for them.

Making a judgement from our own sensory experience, we feel we should try and limit them since it appears to interfere with their ability to communicate. This is to miss the point. Do not try and stop them, or you will make it more difficult for them to understand what is going on.

These self-stimulatory behaviours can be used to give us access as to how the child or adult is feeling, since these are the signals that have meaning for them: how they do the gesture or make the sound reflects their emotional state; I may flap my hands gently or thrash the

air with them - this will either say I am content or I am really upset.

We can use the way they do their activities as an effective language, to build up a non-verbal conversation and engage emotionally with them. In practice we use their body language to communicate empathetically with them. This is known as Intensive Interaction.

Each individual has their own language. The easiest way to learn is to think of how a mother and baby communicate. They do not exactly copy each other but use each other's sounds and gestures to interact. When used with adults, this is not to infantilise our conversation partner but to value them and what has meaning for their brain.

Distressed behaviour usually moderates but there may be individual children for whom sensory issues, pain and even trauma also need to be addressed. This needs more detailed assessment.

The most common sensory issues are visual (with distortions triggered by intense light or bright colours or patterns) in which case they could benefit from a Colorometric Test. If they are having auditory problems, try BOSE Quiet Comfort 25 Noise Cancelling headphones. These can be life changing. They need visual and auditory tranquility. Problems are also an outcome of difficulties experienced when messages are not reaching the brain from the joints and muscles, so the child does not have a sense of what they are doing. They need strong physical messages provided by activities such as trampolining. In my book 'The Anger Box' you will find more details of suitable activities and equipment to help.

So a rough answer to the question is, do not try and stop repetitive behaviour as you will increase their stress level. Look and see how your child is doing whatever it is and respond to their body language to set up an empathetic conversation.

The easiest way to learn is to put aside what you think the child or adult should be doing and join in instead. There are video clips and books recommended on my website www.phoebecaldwell.co.uk and two DVDs, 'Learning the Language' published by Pavilion Publishers, and 'Autism and Intensive Interaction' published by Jessica Kingsley Publishers. The approach also applies to more able children who are semi verbal.



Colometric testing: Tina at Irlen Syndrome East. Tel: 07745 333314

Email: info@irleneast.com

Concept Training Intensive Interaction courses – Tel: 01524 832 828.



Chris Barson

Originally trained as a learning disabilities nurse, Chris joined the National Autistic Society's regional development team before managing professional development and quality programmes for the Royal College of General Practitioners. He later rejoined the NAS as an external training manager before launching the training company Positive About Autism in 2009.

He is a contributing author to 'The Autism Spectrum in the 21st Century: Exploring Psychology, Biology and Practice' published by Jessica Kingsley.

All people really struggle when they don't know what something is or what's happening around them. This is nothing to do with disability, or autism, this is human.

None of us like that 'bump' in the night feeling: a sound from downstairs that's unidentifiable. The 'not knowing' floods our system with adrenaline and the stress hormone, cortisol. Once we have plucked up the courage to investigate, and find out it's just that darn cat knocking over the milk again, we can relax. "It was just a thirsty kitty", you say. Working memory holds on to the 'meaning' of the situation and you can drift off again.

One thing you don't need to do is keep popping downstairs again and again to check you have the 'meaning' right.

But you might if you had autism.

In autism, the brain has a hard time joining the dots together or making a coherent, meaningful picture out of sights, sound, colour and texture etc. It might be like seeing too much of the 'media' but not always getting the 'message'. So when you HAVE autism, and something familiar is available - oh boy - that's a lot less hard work and definitely not scary. When you DON'T have autism your brain is like a message hunter - it locates, absorbs and holds onto meaning easily and doesn't get too troubled or tied up by the media or details.

When everyday situations, people, places, language, images, fail to form up into something that feels like 'meaning,' your brain can't cope. Nobody's could. If you have autism this happens to you a lot.

I think that repetitive behaviour in autism, or spending a lot of time on something that you know the 'meaning' of and find rewarding, is an attempt to make a little oasis of understanding in a desert that is all too often devoid of meaning.

And as such it's just fine. When we let little guys on the spectrum know that they can have access to the things that they value, that we understand and respect those things, they can breathe a sigh of relief. It often transpires that the understanding and respect from the people around them means they might actually need that interest or behaviour less!



Do you have a question for Ask the Experts? E-mail us at editors@aukids.co.uk



You've just been given a host of helpful strategies to encourage your child's independence by someone whose enthusiasm demonstrates that they've probably had more sleep than you. You're feeling strong and determined. Then 8am on Monday morning happens.

Over the years, I've been the best butler my autistic twins could wish for. Eventually, I learnt how to avoid giving them the Five Star treatment. But it wasn't easy.

By Debby Elley

MY twins are perfectly capable of sorting out their own Weetabix in the morning. Sort of. One with a bit of prompting, one with a lot of prompting, gritted teeth, patience and a dustpan and brush.

Forgive my slovenly ways, but 7.15am isn't the time when I want to be teaching them independence skills. Unfortunately, it's the time when most of the independence-type activities take place. Getting dressed, brushing teeth, preparing breakfast.

So for Alec, I'm basically a butler. For Bobby I'm more of a stylist to ensure his shirt collar looks neat, his shoes are on the right feet and his hair is gelled in an artistic way (rather than an autistic way, which is what would happen if I left it to him).

Don't get me wrong, I want my kids to be independent. It's just I'd sooner it happened by magic, without the daily effort it takes to get them that way.

The only thing that stops me in my tracks is the thought that one day these little guys will be 20 years old. Whatever I do now will affect them as young men. Since they reached the age of 12 in the blink of an eye, that isn't so far away as I may like to imagine.

Plus, I know for sure that we need to teach our autistic kids social skills and so it's a bit illogical to assume that self-care is going to come any easier or happen by accident.

To understand why and how you need to teach independence skills, you need to know what's getting in the way of learning them.

Take a passive child, like Alec. Alec is 12 and by rights should be telling me to naff off out of his bedroom. But Alec is used to having a servant who comes in and puts his socks on for him.

It started when he hadn't got the fine motor skills to do it. Now he has, but is slow, partly through lack of practice but mostly because he has been programmed to think that this will be done for him.

And here's the thing: because Alec has autism, he has no concept of what he *should* be doing himself and what I *should* be doing for him.

"If I stop helping just on the odd occasion, Alec doesn't think 'okay I'll do it myself,' he thinks 'Where's the butler?' It's only when I stop helping on multiple occasions, that my expectation changes his thinking."

How does he know that there's a difference between putting a belt on – something that I would help Bobby with – and putting jeans on, which I expect him to do himself? How does he know what a kid his age is *supposed* to be able to do? How does he even know that independence is considered a 'good thing' and something he should be aiming for in life?

We assume that independence is a natural motivation and for many of us it is a developmental step. But the thought 'I want to do it myself,' has to precede that motivation. Some kids may not experience that thought. In others, the task may seem so daunting that the thought quickly fades.

You might want to climb Kilimanjaro yourself, but if you don't feel you're capable, you'll quickly give up thinking about it.

So if there's someone who can do it quicker, why not?

My own expectations are Alec's only signal that this world view is mistaken.

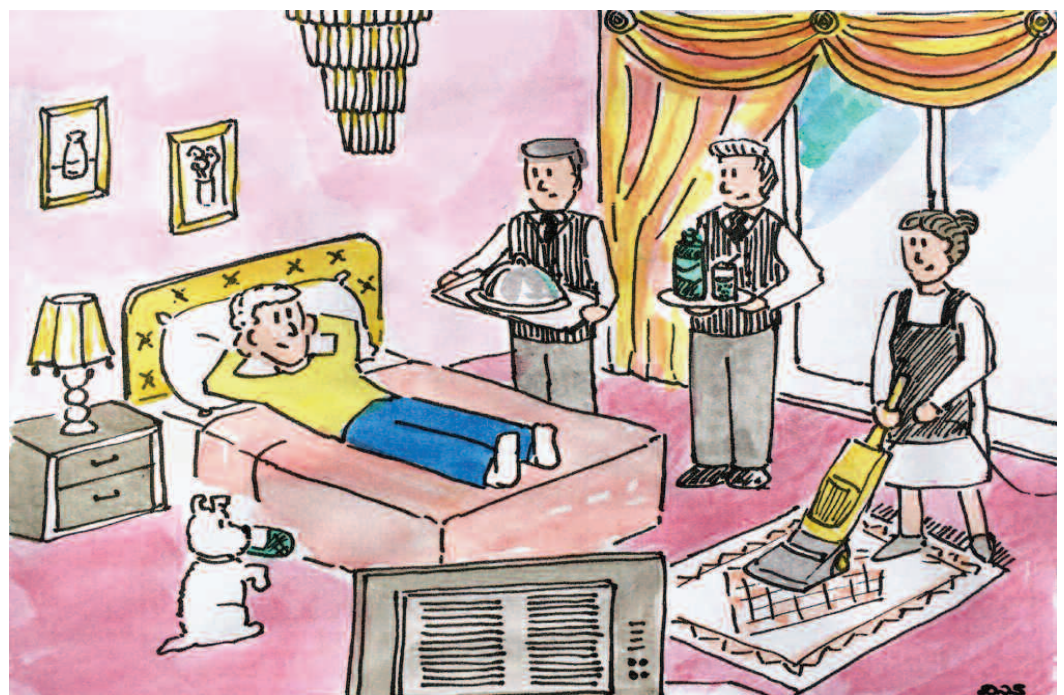
What I've just described is what professionals call 'learned helplessness' or what I prefer to describe as 'The Butler Expectation'. If I stop helping just on the odd occasion, Alec doesn't think 'okay I'll do it myself,' he thinks 'Where's the butler?' It's only when I stop helping on multiple occasions, consistently, that my expectation changes his thinking.

Bobby, on the other hand, has what some might call HFA (High Functioning Autism). In other words he doesn't have learning difficulties and is in a mainstream school. This may lead you to believe that he has more of a clue than Alec when it comes to independence skills. But even folding a pair of pyjamas is problematic. Why?

Executive functioning is affected in people with autism. Our executive functioning enables us to quickly break a task down into visualised smaller steps, then systematically work our way through them. That is why seemingly obvious steps may not be apparent to even the brightest autistic person and some people with Asperger's often appear to be disorganised or scatty.

In addition, focusing on detail rather than the wider picture isn't helpful when you're working to a deadline. Autistic people need structure to help them problem-solve in a linear way.

Now let's add me to the mix. I've got a kid with severe learning



difficulties and helping him with practical things is so much easier than working on anything social. I don't like to see him struggle.

So, the danger with both of our autistic twins is that their dad and I will give up teaching them independence skills altogether. But of course that's not the answer. So what is?

Explain the Whole Independence Story

Bobby used to think that if I asked him to do something, it meant he was expected to be an adult. It's helpful to learn that independence is part of a learning curve that never stops. Explain it in terms of a gradual continuum and not a single target, so that it doesn't seem daunting.

Step by Step Guide

You can do this with written instructions or with symbols, but by breaking down a task into stages you take away the problems caused by lack of executive functioning. For one child, this may mean a checklist of things to get ready for the school day the night before. For another, it may mean a step by step guide to drying themselves after a bath. Checklists reduce anxiety, too.

Keep to a Routine

The key to doing things yourself is having a predictable routine. If the socks always go on after the trousers, and then one day mum holds back and waits, they may try and have a go themselves!

Change the Expectation and You Change the Response

Simply by *expecting* them to do something on a regular basis, however small, you change the

interaction from passive to active. Eventually you come to a place where your child doesn't sit there like a limp biscuit but actively predicts the request and goes to put his or her feet in their trouser legs.

Don't Swallow It Whole

The key is not to eat the cake whole, but to swallow it one bite at a time. Begin with the smallest step they could easily master themselves. Start with a lot of support and very gradually remove the support.

We all learn everything by degrees, the only difference is that those degrees may be smaller and take longer with an autistic child.

You may start by pushing an arm through a sleeve, and work towards touching the arm and saying 'arm' and finally prompting with just the word 'arm'.

In a Rush? Don't Sweat It

Autistic kids feel tension as if you actually were a coiled spring sitting in front of them. Choose a time when your own mood is good.

Slow Yourself Down

Whether it's helping with homework or stepping back whilst they wash their face, count to 20 in your head. As with a lot of autism strategies, playing dumb and pretending you don't know how to do something is also a good way of getting them to think for themselves. Small prompts are better than taking over: "Is it your tie or your socks next, what do you think?"

Show Don't Tell

Instead of describing how to fold pyjamas, life became a lot easier when I demonstrated it to Bobby

Autism Friendly Screenings...

4 films, 4 cinemas, 4 Sundays...every month!

Autism Friendly Screenings are now brought to you at over 200 cinemas, by Dimensions in partnership with Cineworld, ODEON, Showcase and Vue.

www.dimensions-uk.org/autismfilms



and then asked him to copy what I'd just done. Autistic kids are visual thinkers, so don't let language processing get in the way.

Let Them Make Mistakes

Yes it's like watching paint dry when the wrong foot is put into the wrong trouser leg, but you can't learn if you don't have to problem solve.

Let Them Judge Their Own Work

I think about saying "Your tie looks bizarre!" but then I show Bobby in the mirror. Can he spot what's wrong? Have a look in the tie area...

Praise Like Crazy

We've established here that the intrinsic reward of 'I did it myself' and the motivation of being independent isn't necessarily present in our kids. But what they do love is your praise!

Stitch in Time

Yes, you might get a cross child if things aren't done for them! As long as you're not demanding too much at the wrong time and they're praised, that will fade. And this just goes to show that it's even more important to do this whilst they're young.

I've put these tips into practice with Alec and Bobby. In Bobby's case, he is far more independent and that's given him confidence. In Alec's case, it has helped his communication, too. When I did everything for him, he never needed to ask. Now, he has stopped seeing himself as an extension of me and has learnt to ask for help.

So - where to start? With one question - what am I now doing for my child because I have always done it?

Good luck everyone, I look forward to downgrading your Five Star hotel to a lousy B&B!

Breaking News: Bobby just made his own breakfast WITHOUT making any mess...

WITH THANKS TO MY COLLEAGUE TORI HOUGHTON AND DR HEATHER MACKENZIE, WHO BOTH TAUGHT ME HOW TO DOWNGRADE MY OWN HOTEL.



Not A Cereal Offender!

Co-editor Tori, a speech and language therapist, was working with an adult in his 30s whose autism severely affected him and was supporting his parents in increasing communication opportunities. She says: "They ran a Five Star hotel, the breakfast cereal was out on the table before he got up. I asked them what he would do if the Cornflakes weren't out.

"They looked at me and then at each other in horror, as he had been known to be violent in the past. I explained that if it was always there for him, he'd never be able to communicate about it because he wouldn't have an opportunity to request. They took my advice on board and the next morning, left the Cornflakes in the cupboard. They expected him to kick off or get upset, but he just walked over to the cupboard and got the Cornflakes out himself. This was a huge step for both him and his parents!"



The Way to the Land of Nod



Chris Hoyle is the Autism Sleep Clinic Co-ordinator at the Together Trust charity. The Trust's ASC Sleep Clinic has been working with the families of children with autism for 11 years, running parent workshops and working with individual families to provide personalised sleep programmes.

Here are three of Chris's families who overcame sleep difficulties with some simple strategies.

A Long and Winding Road...

Matthew's story by Chris Hoyle and Tina, his mum.

Matthew is 10 and lives with his parents and elder brother. He is academically able with good language skills and will argue and negotiate with his parents. He doesn't understand social rules and finds social interactions very difficult, which means he has few friends. He has high anxiety levels and sensory issues which particularly affect his eating and drinking.

Matthew's parents' entire evening was spent trying to get Matthew to bed and to settle to sleep - which could take between 30 minutes and three-and-a-half hours. They felt that they had no time to themselves.

illustrated narrative showing each step of the new routine. This helped Matthew to understand the sequence and see that he still had time to use his favourite devices. Visual cues to support putting the iPod to charge and turning off devices were also provided. The new routine purposefully had a later bedtime, which can be a useful technique to help children settle to sleep quickly.

'Looking at the morning routine was also important for Matthew as at the weekend he was sleeping in for several hours after his week day rising time. Like many families, Matthew's parents felt they were being kind by letting him sleep in. Restricting the amount of time he slept in, however, would help him to settle faster in the evening. Within two weeks Matthew was settling to sleep on his own by 9.30pm'.

"To settle to sleep could take between 30 minutes and three-and-a-half hours."

The ASC Sleep Clinic Programme

Chris says: 'Looking at Matthew's evening routine was a crucial place to start. It really was taking all evening - starting at 6.30pm and not ending until after 11.30pm. Rearranging it was key. We link going to bed with going to sleep, so the family needed to remove the use of screens once Matthew had gone to bed and reduce the lighting levels at sleep time.

'The new routine was supported with a written visual schedule which mum showed Matthew every evening and an

Tina's comments

"At first we thought the sleep programme was going to be really hard and that we might not get Matthew into the routine with him being so fixed in the routine we had. But we followed all the advice and stuck with it. It wasn't easy to start with, but we persevered. We are so glad we did. It made life much easier for our family and it was also really good for Matthew as he gets a good night's sleep and is in a much better routine.

"The sleep programme was the best thing we have done for Matthew and our family as a whole."

Back in My Own Bed!

Thomas's story by Rachel, his mum

Thomas is 9. He is a happy boy who loves playing Minecraft, Super Mario Kart and being outdoors. He has a syndrome (Smith-Lemli-Opitz) which means he has moderate learning difficulties, is on the autistic spectrum and is deaf with a cochlear implant.

Thomas communicates with a few words and picture symbols. He has had sleep issues since the day he was born and when we approached the sleep clinic, he wouldn't fall asleep in his own bed.

Despite trying every night to settle him in his own bed, he would run out of his room and eventually fall asleep next to us on the sofa. We would then carry him up to bed when he was fast asleep. When he woke in the night, which he did every night, we would take him downstairs and sleep on a sofa bed for the rest of the night. Whilst this routine took away any child-free time, we were relieved Thomas remained calm. This was after several years of trying to keep him in his room while he cried and screamed. However, as he got bigger it was harder and harder to carry him upstairs to bed and we knew something had to change.

After attending the ASC sleep clinic workshop I felt so relieved, relief at meeting other parents whose children had similar sleep habits and not embarrassed or feeling like a useless parent.

Helplessness was replaced with positivity. I left the workshop brimming with ideas and we put some plans into action straight away. We contacted Chris for some more information after the workshop and had a chance to go into



fine detail about Thomas' needs.

Chris tailored the plan to take very slow steps. Using visual schedules and prompts, we moved to Thomas settling in his own bed with us next to him and gradually moving so that we sat on a chair at the side of his bed whilst he settled to sleep in bed. We slowly moved the chair further away from Thomas in his bed and nearer the door.

We have also found it helpful to put a light in his room that can be set to gradually get brighter over 90 minutes before it is time to wake up (Lumie light). Because of Thomas being deaf, it is even harder to communicate with him in the pitch black of the middle of the night. The light has been useful to give him the message that if it is dark it is still time to sleep and if the light is bright it is time to wake up.

The gradual withdrawal from Thomas' room isn't a quick fix and sometimes we have had to take a few steps back but our view was the 'cry it out years' were so distressing for all of us, and we have had 9 years of sleepless nights, so a few more months wouldn't matter. Now my son settles himself to sleep in his own bed within a matter of minutes of 'lights out' as we sit in his doorway and he frequently sleeps all night without waking.

We are now close to leaving him alone in his room to settle.

"As he got bigger it was harder and harder to carry him upstairs to bed and we knew something had to change."

Extra Information



- ‘The light from an iPad is enough to inhibit the brain’s production of melatonin’ – Professor Paul Gringras. Turn off the TV and gadgets at a set time - about an hour before bed if you can. Bath time creates a natural break from gadgets and the beginning of a bedtime routine.

- The ASC Sleep Counselling Service is available at the Together Trust in Stockport – look up www.togethertrust.org.uk and fill in an enquiry form, or call 0161 283 4766.

- Chris’s Sleep clinic workshops are available throughout the year at a variety of North West locations – find them at the Together Trust’s website.

- For some great sleep tips, look up the National Autistic Society’s page at www.autism.org.uk/about/health/child-sleep.aspx

- Download AuKids Issue 15 from our archive to see more from Chris.



- Getting undressed and preparing for bed in either the bathroom or bedroom, and keeping upstairs in the bedroom once the bedtime routine has started will help your child make the link with bedtime and avoid confusion, creating a firm routine. Don’t return downstairs once the bedtime routine has started, even if it means starting it a bit later than previously.

- The Lumie Bodyclock STARTER 30 Wake-Up Light Alarm Clock with Sunrise and Sunset is available for about £50 from Amazon.



- **BOOK:** Sleep and Your Special Needs Child by Antonia Chitty and Victoria Dawson.



It’s Goodnight From Me - and Finally - It’s Now Goodnight From Him!

Kian’s story by Serena, his mum

Kian has some words and uses PECS (Picture Exchange Communication System) and signs to communicate.

His frustration around not being able to communicate as well as sensory sensitivity meant that he displayed some challenging behaviour which was difficult for him and us as his parents. Kian relied on routine and structure; he couldn’t deal with any changes, no matter how small. We found that as long as routines were stuck to, we could have successful outings, but more often than not these proved difficult.

Kian’s sleep problem and evening routine

From the age of about 3, he would go to sleep okay but would constantly wake throughout the night. Sometimes he would just stay awake saying words over and over to himself about games that he liked, or humming songs he liked.

At other times, he would experience night terrors and would often lash out when he woke from these and was difficult to console. This had a knock on effect throughout the day, as he was often tired, not getting into school until late into the morning and sometimes falling asleep in the day. It also had an effect on his behaviour as the tiredness acted as a trigger for meltdowns.

Before the sleep counsellor came, we had used a horizontal picture timeline for Kian’s evening routine. When he got ready for bed and put his pyjamas on, he would often have a bit of time to watch the TV in his room before he went to sleep.

Chris took an in depth history and after we had completed a fortnights’ sleep diary, she devised a personalised sleep programme.



New evening routine and outcome

His new programme involved changes to Kian’s bedtime routine. Once he was upstairs and in his pyjamas, there was no TV and we were given a ‘TV finished’ picture to place on the TV for Kian to see. We were also given a new visual schedule. This used symbols to show Kian the sequence of activities with a ‘finished’ pocket at the bottom for him to put the symbols in once the activity was done. He enjoyed doing this. We were also given symbols for ‘time to sleep’ and ‘morning’.

The outcome for us was instant. Going through the extended timeline with him on the first day, he showed a lot of interest in the new symbols and looked at them for a long time whilst I explained about having a sleep and waking up in the morning.

The first night we implemented the new strategies, Kian slept through the night for the first time in ages! When I went in to

get him the next morning the first thing he said to me was “It’s morning. In the morning you wake up. Phew.”

We stuck to the strategies and Kian started sleeping through the night more regularly. He would have the odd night terror but the advice from the sleep clinic was not to not wake him up and just make sure he was safe, so these didn’t last as long. He is 10 now and sleeps throughout the night and has done since our help from the sleep clinic.

“Now my son settles himself to sleep in his own bed within a matter of minutes of ‘lights out’.”

TOP OF THE BLOGS

We can't pretend we've read all the great blogs out there. But we've come across some darn good ones. Here's some of our favourites.

1 My Son's Not Rainman - BLOG

Who writes it? Comedian John Williams, dad to a 13 year old boy with autism, who performs a stand up show (usually for charity) of the same name. An excerpt from the show was recorded for Radio 4 'Four Thought' and was selected by the BBC as one of their Magic Moments of Radio 2015 as well as featuring on Radio 4's Pick of the Year. John has a book of the same name being published by Michael O' Mara books this September.

What is it? As it says on the site: One man. One autistic boy. A million adventures.

Where can I find it? www.mysonsnotrainman.com



2 Perspectives on Autism - BLOG

Who writes it? Sheffield Hallam senior lecturer in autism, Dr Luke Beardon, for whom we have serious respect – he's one of our own panellists and that's because he's brilliant.

What is it? Sensational musings on autism in every day life, by a professional who lives and breathes the subject. Luke's writing is fluid and colloquial, his passion for autism (as it's lived) runs through the blog like the word Blackpool in a stick of rock.

Where can I find it? blogs.shu.ac.uk/autism



3 Speaking Geek: Translating Typical for the Human Spectrum - VLOG

Who films it? Inspiring author, speaker and Aspie Jennifer Cook O' Toole, whose best selling books are making Jessica Kingsley Publishers very happy at the moment.

What is it? A sort of geek's guide to the universe, an unravelling of awkward social situations and of rules that people on the spectrum may have trouble understanding. Jennifer is a superb life coach for those on the spectrum – and their parents. This blog is an extension of Jennifer's other work at www.asperkids.com

Where can I find it? You can subscribe on You Tube or iTunes – check out this link asperkids.com/speaking-geek

4 Autistic Genius - VLOG

Who films it? Brummie Tom Bowes, who has autism – 'Vlogger, writer, autism advocate, public speaker and generally a nice guy'.

What is it? Autistic Genius is not so much a vlogger as a force of nature. Bursting out of the screen in a flurry of animated arms and facial expressions, he's energetic, engaging, insightful and disarmingly honest. He's obviously had a good upbringing, too, as he brings a raft of tried and tested strategies to the vlog.

Where can I find it? You can follow Autistic Genius on Facebook or Twitter and find his You Tube channel at www.youtube.com/channel/UCdBU3o9ZvID5oadvzLTzsg. He is a busy guy and becoming a popular speaker, so there are some stops and starts, but the back catalogue will keep you amused for ages.



5 Ido in Autismland - BLOG

Who writes it? Ido Kedari, a non-verbal young man with autism, who wrote the book Ido in Autismland at the age of just 16.

What is it? Ido says: I am an autistic guy with a message. I spent the first half of my life completely trapped in silence. The second - on becoming a free soul. I had to fight to get an education but I succeeded, graduating high school with a diploma and a 3.9 GPA (the equivalent of an A - ed). I plan to go to college to continue my education. I communicate by typing on an iPad or a letter board. My book, Ido in Autismland is an autism diary, telling the story of my symptoms, education, and journey into communication. I hope to help other autistic people find a way out of their silence too'.

Where can I find it? Both the blog and a selection of videos are available at idoinautismland.com



6 SENCology - BLOG

Who writes it? A mixture of great education professionals, with plenty of guests. One of the writing team is Gareth Morewood, the inclusion expert interviewed in our bullying feature.

What is it? It's a pool of wisdom on what makes for good inclusion practice in schools. An excellent resource for anyone working in special needs and quite interesting for parents, too.

Where can I find it? blog.optimus-education.com

7 Go Team Kate - BLOG

Who writes it? Mum Shanell Moulard talks about

her two daughters Grace and Kate – Kate has autism.

What is it? Family life described in the coolest way imaginable, by a wise and witty mum with a lot of warmth.

Our favourite bit: Please, take note. Here are the questions I cannot help you with: Do you think I have autism? Do you think my neighbour has autism? Do you think my husband has autism? Do you think my kid has autism? Do you think my car has autism? and Can I get a small loan?

Where can I find it? www.goteamkate.com



8 Neurowonderful - BLOG AND VLOG

Who films it? Amythest Schaber – an autistic writer, artist, public speaker, activist and advocate.

What is it? Amythest blogs about autism, disability, social justice and living a neuro-atypical life. She also writes and produces the series Ask an Autistic on You Tube. We found the series helpful as Amythest has got a beautifully straightforward way of explaining some complex issues surrounding autism.

Where can I find it? The Ask an Autistic series can be found at www.youtube.com/user/neurowonderful and Amythest's blog is at neurowonderful.tumblr.com



9 Sonny Days: Believing autistic children are AWETISTIC - BLOG

Who writes it? Melanthe Grand, probably the best support worker in the universe. Having worked in Sonny's school and left in 2013, she couldn't bear not to see him again. So she became his support worker.

What is it? Mel takes Sonny on adventures around London, and blogs about it. The ups, downs, highs, lows – the lot. Her zest for life and sense of adventure is awesome.

Where can I find it? www.mysonnydays.wordpress.com



10 The Curly Hair Project - BLOG

Who writes it? Alis Rowe, AKA The Girl with the Curly Hair. Cartoonist, speaker, autism advocate. AuKids has published some of her endearing cartoons.

What is it? Alis shares some really good strategies, based on her own experiences. You have to subscribe for some of the content, at a cost of £2.49 a month, but this helps to fund some of the other initiatives by The Curly Hair Project.

Where can I find it? thegirlwiththecurlyhair.co.uk/asd-blog





Olga Bogdashina is an internationally renowned researcher and lecturer in autism and the author of books on sensory perception, the Theory of Mind, communication and spirituality in autism. Her autistic son Alyosha, 28, is the inspiration behind her career.

A paper blog by autism expert Olga Bogdashina

Blog 6

The World With An Extra Dimension

“Two little eyes to look around.

Two little ears to hear each sound,

One little nose to smell...”

We all happily sing these lines with our children. But what if eyes can ‘see’ sounds, ears can ‘hear’ tastes and noses can ‘smell’ colours?

It might sound absurd, but these are the experiences of those with cross-sensory perception, the common term for synaesthesia. Although it isn’t specific to autism, synaesthesia seems to be quite common among autistic individuals.

My son Alyosha was about 9 years old when he tried to account for a panic attack by saying: “I was scared. I saw a yellow ‘z-z-z’ sound.” This was confusing, until I realised he had cross-sensory perception.

Those with synaesthesia may be able to see sounds, or smell colours, or taste shapes, or feel sounds on the skin, or hear colours. Some people may forget the name of a person they know but remember the colour, taste, or even the temperature of the name.

There are many different types and variations of synaesthesia. In two-sensory synaesthesia, stimulation of one sense triggers perception in a second sense. So, someone may complain about the ‘sour taste’ of a neighbour’s voice. This can happen with other combinations of senses.

In multi-sensory synaesthesia, more than two sense are involved. That’s when it gets really complicated! A child may experience the taste of a sound, while simultaneously seeing the colour and experiencing a tickling sensation on the skin.

Usually, synaesthesia occurs in one direction only, so although you may feel a sensation on your skin when you see something, the sensation of touch won’t trigger a visual experience.

On the rarer occasions when synesthesia does happen in two directions, it can cause a person quite a bit of suffering. They can experience stress, dizziness and information overload. Because of this, they may avoid noisy or colourful places, and may withdraw completely.

When my son is in a state of sensory overload, his synaesthetic experiences aggravate his condition and it can lead to ‘panic attacks’ and aggression. Once, he explained: “In the shop I heard ‘black’ then the word broke down into pieces and they entered my eyes. I became blind because everything was black.”

At the time I was bewildered with this, and placed his ‘reports’ into the category ‘confusing’. But in 2011 I came across an account by Brian King, a social worker who is on the spectrum himself, as well as the father of three autistic children.

King reported that when he is listening to someone speak, he can see each word; words scroll through the air in front of him. If someone repeats a word in a conversation Brian sees it in a darker colour; and if his communicative partner emphasizes that word while speaking, it literally jumps out at him in 3D.

So Alyosha sees not only colours in response to sounds, but also words when he hears them. If he sees the ‘wrong word’ (or as he says his ‘eyes see the wrong word’) we are all in trouble. His panic attack is not far away, and the consequences may be unpredictable.

One of my earliest experiences of synaesthesia was during my teaching days at the day centre for autism which I founded in the Ukraine. I brought some coloured alphabet blocks into the classroom for some fun learning. But seven year-old Lena definitely didn’t think this idea was much fun. She

grabbed a block and threw it across the room.

“The colour is wrong! ‘C’ isn’t yellow, it’s brown!”

Synaesthesia can indeed involve letters, words or numbers being experienced as colours. Sometimes numbers are experienced as shapes or forms. In the fascinating book *Born on a Blue Day*, autistic mathematician Daniel Tammet describes experiencing numbers as cities which he can walk through.

There are still more puzzling variations. Even abstract concepts, such as maths problems, can be perceived as shapes or colours. So, the answer to $6 + 3$ may be ‘green’!

Interestingly, synaesthetic experience is individual; for example, among people who see coloured sounds there is no particular colour that is universally heard for each sound.

This mysterious condition is not easily detected because many autistic children with it don’t realise

that other people don’t share the same experience. To them, it’s normal. Even very articulate adults with autism find it difficult to express their experiences when they are so different from everyone else’s.

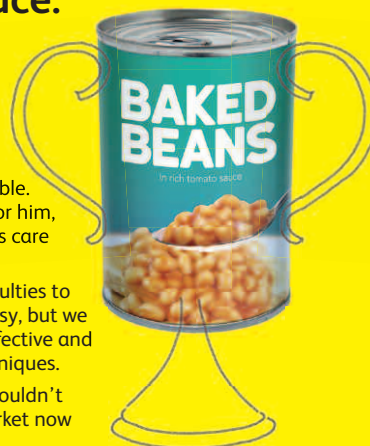
For many, though, synaesthesia can be a distinct advantage. The artist Kandinsky famously had this condition and contemporary celebrities such as Pharrell Williams, (whose hit *Happy* he reports is ‘yellow with a hit of mustard and sherbet orange’) also use it for creative purposes.

If it’s puzzling for us to understand synaesthesia, what must it be like for autistic people to understand us?

It must be so confusing - why can’t we see a range of colours in a noisy environment, and words floating between us?

Editor’s note: Tim Tuff, who works for AuKids, ‘sees’ words when he hears them and they have the ability to cause him pain or discomfort.

This isn’t just a tin of beans. It’s a milestone. A massive victory. A success story in tomato sauce.



For one of the young people we care for at Hesley, the thought of going to the shops to stock up on weekly groceries was unthinkable. A constant challenge for him, his parents, his previous care providers, but not us.

There were many difficulties to overcome. It wasn’t easy, but we got there by finding effective and innovative coping techniques.

The young man who wouldn’t step foot in a supermarket now shops for himself.

Find out more about our schools and colleges visit www.hesleygroup.co.uk or call **0800 0556789**.



Established in 1975, the Hesley Group provides specialist support through its schools, colleges and adult residential services 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.

How Smart Schools Stop Bullying

It will come as no surprise that research shows pupils with autism are far more likely to experience bullying at school than other youngsters. But the actual figures make shocking reading. One study reported the prevalence rate at an alarming 94%*. So how can schools, parents and pupils themselves reduce this dismal statistic? Here's how...



Smart Parents...

Spot Early Signs of Bullying

Missing clothes, equipment or money; bruises or scratches; being reluctant to go to school; appearing stressed or showing an increase in obsessional or repetitive behaviour; showing a poorer standard of work or difficulty sleeping. These are just some possible signs that should be investigated further.

Are Open with School

Report behaviour changes at home at the first sign of trouble and have a chat with school, keeping an open mind – school may not be aware.

Keep in Touch

Joint strategies and consistency can be very helpful and a good knowledge of school's interventions, plus a trusting relationship, is key to adapting strategies when things get tough. So keep writing in the home school diary, or emailing your child's Teaching Assistant, even when things are going well.

Teach Kids to Identify Their Emotions...

by talking about feelings as they're being expressed.

Build Self Esteem... by showing them how their autism can help them and recounting stories about successful people on the spectrum. Spotting and pointing out their skills and praising good social awareness.

Listen Regularly

Create a space in the evening where the child with autism talks about their day, whether it's been good or bad.

Smart Peers...

Are Educated in Autism

Have an understanding of what autism is and why their fellow pupils behave in certain ways.

Are Encouraged to Help

It's not just the Teaching Assistant doing all the supporting (which can lead to isolation), it's peers being encouraged to support each other and being rewarded for doing so.

Can Identify and Report Bullying

They are part of a zero tolerance culture.

Celebrate Difference

In a school environment, it's all about fitting in with the crowd. If peers are to celebrate difference, then individuality needs to be identified as a strength.



Smart Kids With Autism...

Understand Themselves

They're aware of what their autism means to them, know their strengths and challenges and have a range of coping strategies. Through home and school education, they develop an understanding of how their own behaviour impacts on others.

Understand Bullying

They are taught the difference between an innocent mistake and being targeted and this helps prevent over or under reporting.

Understand Social Cues

Are able to recognise warning signals in themselves and others. They have self-calming strategies and know when to walk away from a situation, or what to say when provoked. This comes with good intervention from speech and language therapy and also at home.

Can Deal with Provocation

If violent outbursts when provoked cause knock-on problems, schools can focus on rehearsed ways of dealing with a situation, with strategies, a structure and visual prompts.

← **BACKCHAT:** Humour and resilience can deflect bullies. They are only interested in people who take it to heart.



A Smart School...

Reduces Risks

"No school can stop bullying entirely," says Gareth Morewood, Director of Curriculum Support at Priestnall School in Stockport. "What we can do, however, is put strategies in place to significantly reduce the risk of it happening". This means predicting where and why it can typically occur.

Educates Other Pupils in Autism

Through whole school assemblies, peer talks and life education lessons, they give a detailed explanation of what autism is, why pupils may behave the way they do within the school environment and the support that they need in order to 'create a level playing field'. This prevents jealousy and isolation. One study showed that even a basic explanation had a profoundly positive effect on whether children were likely to befriend a pupil with autism**.

Gives Other Pupils a Clear Understanding of What's Acceptable

Smart schools constantly promote zero tolerance to bullying and give regular reminders of what unacceptable behaviour towards others is, so that children are able to identify and report bullying.

Has Anonymous Methods of Reporting Bullying

A bullying box, for instance, can encourage secret reporting of incidents, although it shouldn't be used as sole evidence.

Prevents Isolation

By providing lunchtime clubs, buddying schemes or friendship benches where children can sit if they need someone to play with. Some schools have a *Circle of Friends*, a small volunteer group of pupils identified to help autistic pupils with social skills and look out for them.

Has a Culture of Inclusion

This means that difference and diversity is celebrated at every opportunity. All pupils' work is displayed and autistic children are given a chance to shine. For instance, at Priestnall School in Stockport,

the school has a Manga Club, in which pupils with autism take lead roles in supporting peers to develop work on projects and pieces of art. It also has a Lego Therapy club run by one of its speech and language therapists, which is very popular.

Promotes Positive Role Models and Challenges Stereotypes

In one school, a film of the famous autistic artist Stephen Wiltshire was played, showing him drawing St Paul's Cathedral from memory. Pupils were then asked to attempt the same in five minutes!

Encourages Communication

Restorative approaches, where pupils are encouraged to talk situations through with each other with support and structure, are more effective than punishment and address the root causes of bullying.

Identifies Vulnerable Times

Unstructured times such as break and lunchtime are catered for, by allowing vulnerable pupils to use a computer or library, or providing structured playground activities.

Selects Good Teaching Staff and Trains Them in Autism

Staff show understanding and acceptance, are flexible and adaptive and encourage differences – and pupils pick up on their lead***.

Jumps on Problems Quickly

You can't always predict a situation, but once it happens a good school will adapt quickly to prevent a recurrence.

Considers Seating Plans

Teachers, rather than pupils, choose where pupils should sit. Pupils are placed in the classroom giving particular consideration to vulnerable ones, who may have supportive peers placed near them.

Has Trusted People to Turn to

Gareth Morewood refers to 'corporate responsibility' in relation to autism, meaning that at every level of the school a variety of adults and peers can be approached. Pupils should be able to identify a handful of individuals they can confide in safely.

Further Support

- Bullies Out is an anti-bullying charity that offers education, training, awareness and support to anyone affected by bullying. The organisation's Young Ambassador programme is open to anyone between the ages of 10-21 and provides a vehicle for young people to get involved in its anti-bullying campaign. www.bulliesout.com
- Kidscape at www.kidscape.org.uk provides a helpline for parents of children who are being bullied.
- Beat Bullying at www.beatbullying.org has information and advice on dealing with bullying for children, parents and professionals.
- The Anti Bullying Alliance produces good materials to support schools. www.anti-bullyingalliance.org.uk
- Lesson plans for autism awareness from the NAS can be found here: www.autism.org.uk/professionals/teachers/lessons-breaktimes/lesson-guide.aspx
- The Anti-Bullying Network at antibullying.net is a Scottish organisation providing support to school communities.
- Bullying Education Support for Northern Ireland - www.education-support.org.uk

AuKids would like to thank the following sources for their help in production of this article:

- Gareth Morewood, Director of Curriculum Support at Priestnall School in Stockport.
- Neil Humphrey, Professor at the Manchester Institute of Education, University of Manchester and Dr Judith Hebron, a post-doctoral research fellow at the Manchester Institute of Education, University of Manchester. Their paper *Bullying of Children and Adolescents with Autism Spectrum Conditions: A State of the Field Review* was published in the *International Journal of Inclusive Education*.
- Greg Loynes, Admissions, Transitions and Outreach Manager, Inscape House School, Cheadle, Cheshire.
- The National Autistic Society, whose excellent and extensive online guidance on bullying, including creating a Circle of Friends, can be found at: www.autism.org.uk/bullying It includes how to tell if your child is being bullied, what to do if your child is the bully, bullying interventions, online bullying and how to approach the school.
- Contact a Family for its publication *A Guide to Dealing with Bullying: for Parents of Disabled Children*. The guide is available to download at www.cafamily.org.uk or call 0808 808 355 for a free printed version.

Research:

*Little's 2002 survey in the USA found that 94% of mothers of children with AS and non-verbal learning disorder reported their child to have been the victim of bullying during the last 12 months.

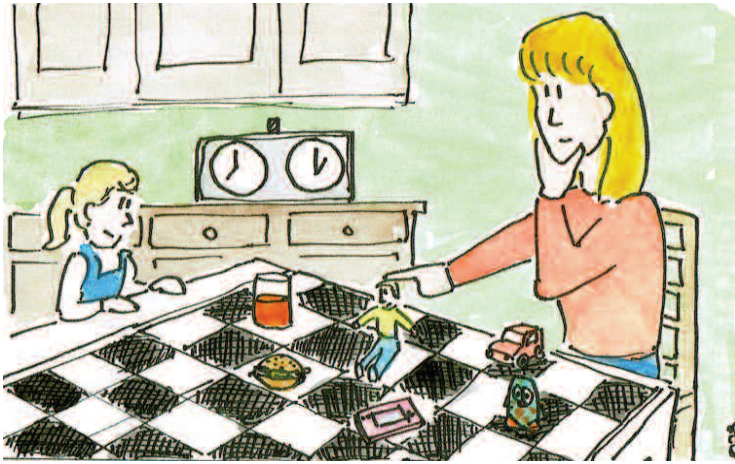
**Campbell, J.M., J.E. Ferguson, C.V. Herzinger, J.N. Jackson and C.A. Marino 2004: 'Combined Descriptive and Explanatory Information Improves Peers' Perception of Autism. Published in *Research in Developmental Disabilities* 25 (4): 321-339.

***This view is supported by the research of Robertson, Chamberlain and Kasaris (2003) who found that the quality of teacher-student interactions influenced relationships, which in turn had a bearing on peer acceptance for children with ASC'. From Neil Humphrey and Judith Hebron's paper *Bullying of children and adolescents with autism spectrum conditions: a 'state of the field' review*. Published in the *International Journal of Inclusive Education*. [dx.doi.org/10.1080/13603116.2014.981602](https://doi.org/10.1080/13603116.2014.981602)



The Last Word

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



Six Steps to Sanity

There's a book by Naoki Higashida called *The Reason I Jump*. We've reviewed it in *AuKids* and it's a great insight from the personal perspective of someone with autism, although not a universal description of the condition.

I'm thinking of writing my own version, called *The Reason I'm Sane*, a personal perspective of the condition known as *Being A Neurotypical Mum*.

The central trait of *Being A Neurotypical Mum* is a tendency to think six steps in advance. This isn't a skill I was born with, but one borne out of a need to do so in order to avert some sort of disaster. You have to have experienced a fair few disasters before you learn the Six Steps in Advance method, but believe me when a learning curve is this painful, it doesn't take long.

This morning was a good illustration. I had decided to take Bobby to the uniform shop. Yes, it's only the beginning of June. Tip one, don't take your autistic child to either a shoe shop or a uniform shop when the place is heaving with other parent/child partnerships.

Tip two, if you have two autistic kids, don't take both if you can leave one at home, unless you want to make the 30 second dash to the front door of the shop to rescue one whilst the other, somewhat encumbered by the narrow space in the changing rooms, is kicking the mirror in trying to get a pair of school trousers on.

So, with Gavin at home, I had the opportunity to visit the shop with just the one twin, even though Bobby still managed to kick the changing room mirror during a decidedly off-balance moment.

Tip three, call the uniform shop to

check it's open beforehand. I've missed this step out on a couple of occasions, assuming in a blithely optimistic manner that it follows the traditional pattern of being open during the day. It doesn't. It's usually closing its shutters just as I reach its front door.

I was three steps ahead by now, only the shop owner wasn't quite used to this and half his seasonal stock wasn't in yet. Still, it was worth the trip, as he was the only audience member witnessing Bobby's changing room meltdown as he 'couldn't handle the pressure' of being asked whether he thought these fitted any better than last year's trousers.

Already three steps ahead, there was a bit more future planning to come. It's Friday and I'm going to visit my friend in Birmingham for my three-monthly Sanity Restoring Break.

On Monday morning it'll be Week B in Bobby's timetable, which means P.E., which means taking his clothes off and without a shadow of a doubt losing his new trousers unless I iron on a name tag without further ado.

Six steps in one morning – is it a record?

It's a bit like playing a constant game of chess, predicting our children's likely moves and, with head-swivelling speed, adjusting our own actions to fit.

Well, the trousers didn't fit after all. And I didn't get to visit my friend, since our entire family came down with the same 24-hour bug at the same time.

So much for head-swivelling speed. It turns out I'm not half as clever as I think I am.

Think that's what you call checkmate.

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Support for me and my family

Our family support services offer a wide range of advice, training and free advice drop-in sessions



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