

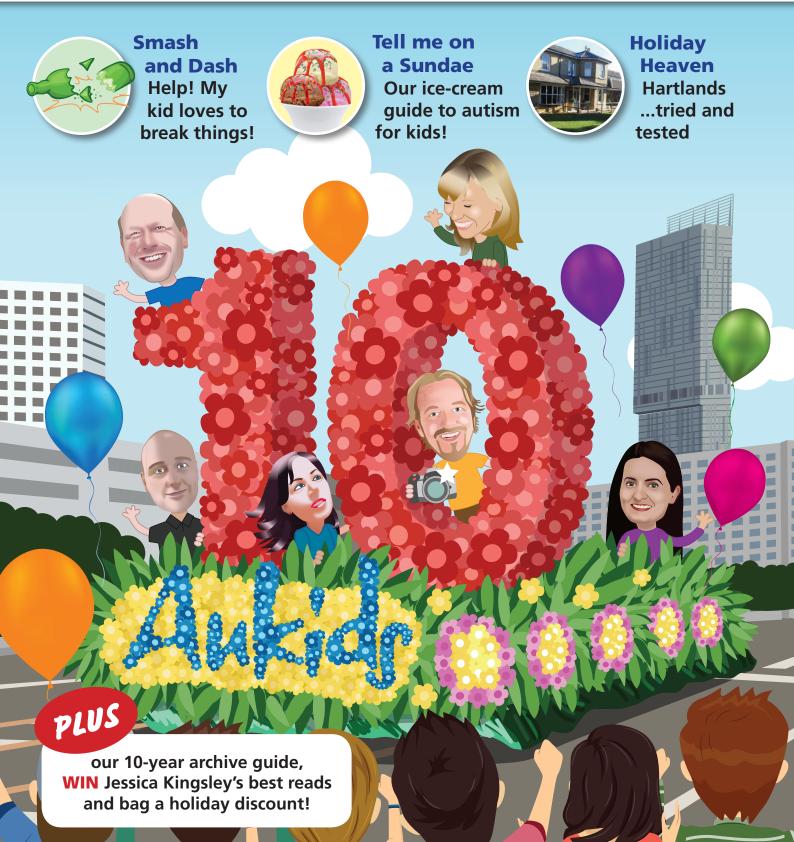


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# 10<sup>th</sup> Anniversary Issue



# Letter from the Editors



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#### dimensions Autism friendly

## **▼** dimensions

and putting in place a number of sensory friendly adjustments, we're helping create a more accepting and inclusive society for

Linemas We work with ODEON, Cineworld, Vue and Showcase at over 300 cinemas nationwide

Once a month, each cinema hosts an autism friendly cinema screening welcoming families, friends and individuals to their sensory friendly

#### Libraries

We've produced a training video and suite of resources to help libraries across the country become autism friendly. These are free for all libraries to use, should they choose to do so.

Ask your library to become autism friendly and show them how important the changes are for you.

We work in partnership with the Association of Senior Children's and Education Librarians and the Society of Chief Librarians to support autism friendly libraries, in a project funded by the Arts Council of England.

Belong by GAME

We're also working with Belong by GAME to trial autism friendly adjustments at thei

Belong Arenas are separate areas at some GAME stores where customers can play the latest video games on the latest equipment –including high tech gaming PCs, Playstation

elong Arenas are already quiet, welcoming spaces where some people with autism go to meet new people and try new games.

# 10<sup>th</sup> Anniversary Issue!

AuKids started up in 2008 as a local magazine with the aim of sharing great information with parents of autistic kids. We were the first autism parenting magazine in the UK and the dual perspective of a parent writer (Debby Elley) and professional advisor (Tori Houghton) has given our magazine a reputation as the one to read for autism as it's really lived.

We remain just a small team with a few key aims; to bring together the best advice on autism, to simplify jargon and to provide you with practical strategies for success. If you want to read a bit more about us, check out our website at www.aukids. co.uk and click on Who Are We?

In 2015, AuKids won Specialist Magazine of the Year at the Prolific North Awards. In 2016, we won the Federation of Small Businesses Social Enterprise of the Year for Manchester and East Cheshire. Last year, we were voted third in Vernon Building Society's Jubilee Awards. This year, we were once again shortlisted for the Prolific North Awards. We're doing something a little different, and it's wonderful to be celebrated for it.

To fundraise for the magazine, we give talks within the autism community and run autism awareness courses for businesses and charitable organizations across the UK. We've also hosted some great events for our readers, and we'll continue to provide you with exciting entertainment. Never let it be said that AuKids relies on a raffle!

On a personal note, the co-editors of AuKids have seen their careers – and families – expand within the last decade. Having consolidated her reputation as an autism writer through AuKids, co-editor Debby Elley published 15 *Things They Forgot to Tell You About Autism* earlier this year and now writes articles for other magazines. Meanwhile co-editor Tori Houghton's autism support agency, Time Specialist Support in Manchester, has expanded and now

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. employs nearly 100 support staff. It marks its tenth birthday this year, too. Tori's also become a mum... and so has Jo our graphic designer - twice! It's been a busy decade!

We've seen many changes in the world of autism, too.

The rise of autism-friendly shows has been the most noticeable social change. After Odeon kick-started a huge autism-friendly initiative, other cinemas followed suit and theatres weren't far behind. Department stores are the latest to adopt 'autism hours' to help shoppers who may experience overload. Whilst nothing is perfect, we shouldn't take these major changes for granted – they are unheard of in other countries.

In the last ten years we've also seen the law updated, with the Equality Act 2010 giving autistic pupils (among others) the right to be fully and actively included in school life. Plenty more work needs to be done, but having the spirit of the law behind us is certainly a start.

The introduction of EHC Plans has aimed to bring all branches of support 'under one roof' for our kids. Meanwhile the Autism Act of 2009, driven by our National Autistic Society, aims to address the needs of adults with autism in the UK, many of whom are out of work for no good reason. The work now being done to translate law into policy will stand our own generation of children in good stead.

Our understanding of autism has rocketed and there are now books on every aspect of autism. Help and advice is much easier to come by than it was a decade ago.

And what is AuKids' place, a decade into all this change? We consider ourselves the 'big sister' for parents like you. With a finger on the pulse when it comes to translating what's out there, and a background of solid experience, we hope to bring you the best advice in a friendly and easy to read package. And as long as we continue to receive your lovely letters, we'll continue to be here for you. Enjoy this special celebration issue!

Tori & Debby

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# READERS' PAGE

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

# Where Are They Now?

For our 10<sup>th</sup> anniversary issue, we thought it would be fun to find some of our early front cover kids and see what they're up to now. Wow, how time flies!



JOSHUA was 8 when his photo was taken for our first birthday issue in Summer 2009. At the time, his loves were 'SpongeBob, Ben 10, singing, playing my piano and reciting movie scenes. I have a real obsession with adverts for cleaning products and I am always telling mummy at the supermarket what products to buy and how they work.' His mum described him in four words as happy, musical, energetic and chilled.

Joshua is now 17 and attends Macclesfield college studying music and performing arts. He is hoping to one day go to Manchester Metropolitan University to study music.

His mum Lesley says: "Joshua has amazed us with his progress the last few years. He certainly has a gift for singing and songwriting and recently was the star in his end of term performance, composing and playing all the music and giving 80s hits a 1920s vibe.

"College has been the making of him and for the first time ever he's asking for friends to come over and has had a few student parties! He still struggles with certain aspects of day to day life and communicating information from college to home is still a task we fall out over, but



the support he receives from there is excellent.

"He sat his GCSEs and left high school with good grades and with a B in music and was nominated by his peers as the Prom King, which is testament to his personality and likeability.

Seeing how far he has come on already, I think the world is his oyster. I'm one very proud mum!"



**SOPHIE** was only 4 when she appeared on the front of our Autumn 2011 issue. At the time her interests were swimming, singing action songs, books and bedtime stories, food and running about in open spaces! Her grandma Mary says: "Sophie is now 10 and still the happy, healthy little girl that she always was. She loves to be either in the garden or travelling on buses, trains, trams or riding in the car.

"Her favourite pastime is still swimming for which she has her own 'style'.

"Sophie goes to Grange School in Manchester and really enjoys it (and would go seven days a week if she could). She still loves her bedtime stories, too".



**ED** was 8 when we photographed him for Issue 5 in Autumn 2009. His main passion then was movies, especially Disney Pixar ones, and he collected movie posters. His mum Katie then described him as happy, lovable, funny and determined. Ed is now 16 and has just finished his GCSEs. Katie says: "He really enjoyed high school and particularly loved graphics which linked with his 'forever love' of all things film related.

"Ed's tastes have moved on from pure Disney and now encompass all film makers and all genres - from the classics like Singing In The Rain to the less acclaimed Sharknado! The Lego<sup>®</sup> movies have been particular hits as they include his second favourite pastime of Lego<sup>®</sup> building.

"Ed loves to review movies and films his own review shows. He has made a number of stop-motion short films and celebrates the best and worst films of the year with his own version of the Oscars - The Edscars!

"He is gearing himself up to applying these skills in a Creative Media course at college in September, where he will also be able to use his gaming skills to good effect. As for the future, watch this space but he is certainly ready for the next episode..."

### Who's on the Cover?

- 1 Tim Tuff Research & advocacy
- 2 Tori Houghton Co-Editor
- 3 Paul Clare Printer
- 4 Debby Elley Co-Editor
- 5 Dave Laslett Photographer

6 Jo Perry - Graphic Designer & illustrator

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If you have any questions relating to this or need a username and password reminder, email admin@ aukids.co.uk and we'll be happy to help you.



The Autism Books That Made (My) Publishing History

Year

Years

Years

Years

Years

Year

Pears

JESSICA Kingsley has been at the helm of her own independent publishing company since founding Jessica Kingsley Publishers in 1987. Her mission was to boldly go where no publishing house had gone before, tackling a range of social and mental health issues by creating books that made a real difference to its audience's lives. With offices in London and later Philadelphia, JKP has produced 800 books on autism and publishes around 50 books a year on the subject.

JKP became part of the John Murray Press division of Hachette Group in 2017, following Jessica's decision to retire from the company after more than 30 years as its director. With the backing of the second largest publishing group in the UK, the company can be assured of a bright future.

As Jessica herself bows out of the limelight and into an active retirement this month, we asked her to share with us some of her favourite titles – and those that represent the changes in our understanding of autism over the last three decades.

By Jessica Kingsley

Although JKP is probably best known for publishing books on and around the autism spectrum, this is just one of overlapping and interrelated subjects that we cover.

The autism list came about through a combination of chance events. The Scottish

Office offered us our first (fascinating) book on the subject in the early 1990s. As a result of this, the late Donna Williams' *Autism: An Inside-Out Approach* – her first book aimed at professionals - came to us.

She and I had a long lunch, over which Donna - one of the most charming and intelligent people I have known - explained amongst other things about the sensory issues in autism, which was both a revelation and a dawning recognition for me. As I began to explore the subject of autism, it became clear just how little the general public understood it and how much it was misinterpreted, misunderstood and feared. Obviously, this was a situation that good books could help to change, and from that moment JKP started working to create a collection of positive, truthful and practically helpful books.

Initially we thought in terms of publishing for teachers, social workers, psychologists and others who encountered autistic people in their professional lives without necessarily realising it, and almost certainly without understanding it well. But we soon found that these books were just as popular and valuable to parents.

Tony Attwood's first book - **Asperger's Syndrome: A Guide for Parents and Professionals** - was absolutely a case in point, as was his later book **The Complete Guide to Asperger's Syndrome**, which is still in the JKP best seller list after ten years.

Tony's compassionate and positive approach, and his deep and genuine interest in the people as well as the condition, chimed exactly with the JKP ethos, and his help in identifying new and important issues and supporting the list has been invaluable.

My friendship with the amazing Jackson family grew out of the publication of Luke Jackson's first book (at the age of 11) on the gluten free diet, and reminded us again how brilliantly people on the spectrum can write, and how absolutely nothing can replace the inside story. We published Luke's second book - *Freaks, Geeks, and Asperger's Syndrome: A User Guide to Adolescence* - to huge acclaim.

Publicity for the book included the cover of the Saturday Telegraph colour supplement, and showed just how much such a book was needed, and how well it worked in explaining autism. Luke (then aged 15) gave an incredible speech at the JKP 15<sup>th</sup> anniversary party; there was hardly a dry eye in the house, and almost 20 years later everyone who was there still remembers it vividly. For me, a victory for autism, and *Freaks, Geeks...* is known and still used all over the world.

"One of the things that has always struck me about people on the autism spectrum is how almost all of them really want to help other people".

. . . . . . . . . . . . . .

Our horizons expanded and it became clear there were other ways to publish, and different ways to communicate about autism. Kathy Hoopmann's wonderful *All Cats Have Asperger Syndrome* continues to be picked up wherever people see it (*'Awe, isn't that cute?'*), but the message is real. This kind, humorous, gentle visual introduction to what autism is really like has changed innumerable lives for the better, and goes on doing so. Her new book *All Birds Have Anxiety* carries on this work and is already winning awards.

We saw that books for children were a brilliant medium for creating change: for children with autism, for their peer group, and somewhat more subversively for families and people such as teaching assistants, whose understanding of autism deepened as they read these with children individually and in classrooms.

The first of these, and still hugely popular, was Kay and Haitham Al Ghani's **The Red Beast: Controlling Anger in Children** with Asperger's Syndrome. We've also started exploring fiction, comics and workbooks.

The children who were part of the first cohort diagnosed with Asperger Syndrome grew up to be teens and adults, and they and their successors needed books on different issues. Jennifer O'Toole's **The Asperkid's (Secret) Book of Social Rules** proved another classic that has helped successive generations. We also realised that many more people were being diagnosed as adults, so we turned our attention increasingly to issues such as employment, independent living, and especially relationships. Then came the understanding that women had been hugely under diagnosed. Rudy Simone's *Aspergirls* has been the 'go to' book for newly diagnosed women for years and the core of a collection of books for and about women and girls on the spectrum. Another of my favourites is Cynthia Kim's 2014 *Nerdy, Shy and Socially Inappropriate*, which is funny, intelligent and really helpful.

One of the things that has always struck me about people on the autism spectrum is how almost all of them really want to help other people - indeed, it's a thread that runs through much of the JKP autism list. **Been There. Done That. Try This!** really sums this up - a collection of writings by people on the spectrum about particular issues, offering information, advice and support. At the end of each chapter, a section by Tony Attwood offers more information and professional advice.

I'm really looking forward to the girls' version of this, coming out later in 2018 - **Spectrum Women: Walking to the Beat of Autism**, edited by Barb Cook. It follows the same format, all the international contributors are women, and the professional advice is by Dr Michelle Garnett from the Minds and Hearts clinic in Brisbane.

And of course the challenges don't go away - Debby Elley's lovely *Fifteen Things they Forgot to Tell You about Autism*, Siobhan Timmins' Social Stories books through the lifespan (*Successful Social Articles into Adulthood*), and Maria and Miguel Gallardo's awardwinning *Maria and Me* all address the perennial questions, but in fresh new ways.

Most recently, JKP's authority in the world of autism, and the amazing support the list has from the autism community, has enabled us also to take on some of the darker aspects of autism - the mental health issues that can plague anyone, but perhaps particularly people for whom the world is often if not always just so darn difficult.

We have also looked at what happens when people on the spectrum tangle with the criminal justice system, especially in relation to how this can be the result of misunderstanding but also at how difficult life can be once in the system. I think Will Attwood's book *Asperger's Syndrome and Jail: A Survival Guide*, due out in 2018, will not merely be an important book, but also a life saver for some.

What does the future hold? I know the JKP ethos of friendship with and respect for our authors, and for the autism community, and the absolute insistence on high quality information will not change. I think we will see more books exploring brain function, creativity, and solutions for living in the list, but also some of the more difficult topics addressed, and at the same time more publications that both amuse and inform.

I don't think JKP is going to stop trying to change the world!

# Five of Jessica's Favourites!

To celebrate Jessica's 30 years at JKP, we're giving away five of her favourite books to TWO lucky winners!

# The prizes are:

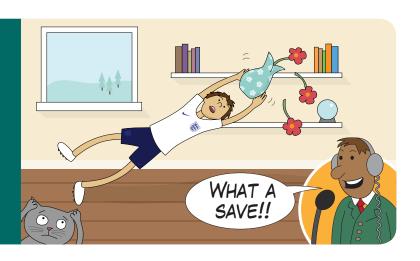


To be in with a chance of winning this exciting package, all you have to do is to tell us what animal features on JKP's logo. Find it at www.jkp.com

E-mail your answer with your name, address and 'JKP' in the subject header, to competitions@aukids.co.uk or pop a postcard in the post to AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE no later than August 31<sup>st</sup> 2018. Winners will be chosen at random after the closing date. Please note, only winners' names and addresses will be forwarded to JKP so that they can send you your prize directly. Good luck and happy reading!

# Ask the Experts

### My son breaks everything. We are getting extremely good at diving to catch things and I have the reactions of a world class goalie now. He has little understanding and we are not sure what he is taking on board. It's getting expensive.





#### **Breanne Black**

Breanne is a Specialist Paediatric Occupational Therapist at Cool For Kids Occupational Therapy. www.coolforkids occupationaltherapy.co.uk

E-mail: yazaboo@hotmail.co.uk

# **Possibility 1**: He breaks things because he doesn't know his own strength.

From a sensory perspective, the ability to use your hands and fingers (fine motor skills) are dependent upon having accurate sensory feedback from a combination of two senses. The tactile system is made up from receptors in the skin. They provide information about touch sensations: pressure, vibration, movement, temperature and pain.

The tactile system has two main purposes: a protective function and a discrimination function.

The protective function protects from danger, recognising pain and temperature.

The discrimination function informs us of what we are touching - its size, shape, and texture. More importantly, it gives us the information required to support visual perception, motor planning and body awareness.

The other sense involved is the proprioceptive sense. Proprioception receptors are located within our muscles, joints, ligaments, tendons and connective tissues. Proprioceptive sense provides our bodies with information about whether our muscles are being stretched, or our joints bending and straightening and how much and how fast this is occurring.

The main purpose of the proprioceptive system is to provide our bodies with information that allows us to plan, grade and control motor movements - for example to know where to position our hands when sitting on a push along toy (without having to intently look). It also allows us to be able to judge how much force or pressure is required when handling objects, so you don't squash a cake when you remove it from its paper case.

Things you may see when these systems are not providing accurate sensory information include:

- Walking too hard
- Writing too hard
- Playing too hard or too loosely with objects
- Playing too rough
- Frequently breaking items.

# **Possibility 2:** Gaining sensory satisfaction from breaking objects.

In terms of obtaining sensory satisfaction from breaking things, this may tap into several senses. AUDITORY: The sound feedback as an object crashes to the ground provides extra levels of auditory feedback.

TACTILE: The sharp, soft, squidgy, wet sensation that is left on your hands as an item breaks provides additional sensory feedback to the skin. This may even be beneficial in waking up the sensory receptors that have gone to sleep.

PROPRIOCEPTIVE: The extra deep pressure you feel as you crash the object against your hand provides your hand with feedback as to where your fingers are - it may even help you feel calm.

#### SATISFYING SHATTER:

The shattering of pieces provides additional visual feedback.



The common theme to both possibilities is an under-sensitive sensory system which is seeking out additional levels of sensory feedback.

#### So how can we help?

Try to fill the day with as many sensory activities as possible with the aim that if you are meeting the need for extra sensory feedback, they are less likely to try to obtain it by breaking things.

Another benefit of this - the activities which provide enhanced tactile and proprioceptive feedback may help them to develop more accurate tactile discrimination and proprioceptive awareness in the long term, leading to fewer breakages!

Activities to provide extra auditory feedback: Cause and effect toys, such as musical instruments and clapping games.

Activities to provide extra visual feedback: Bubble tubes, Kaleidoscopes.

# Activities to provide additional tactile proprioceptive feedback:

- Bean bag chairs (Amazon)
- Play tunnels (Amazon)
- Theraputty
- (www.nrshealthcare.co.uk) • Body Sox
- (www.sensorydirect.com) • Vibration toys (www.multi-
- sensoryworld.co.uk)
  Tactile and resistive fidget items e.g. stress ball (www.
- sensorytoywarehouse.com)
   Theraband (Amazon or www.nrshealthcare.co.uk)
- Baking, mixing and kneading with hands
- Playing in wet sand
- Messy play
- Wiping tables
- Brushing/mopping floors
- Activities which encourage weight bearing to the hands
   e.g. wheelbarrow walks, wall pushes.

#### Activities which specifically work on tactile discrimination:

- Tactile Dominoes
- (www.specialneedstoys.com) • Tactile stepping Stones
- (Amazon)

These are just general ideas, a full sensory assessment from an Occupational Therapist would be recommended in order to devise a bespoke sensory programme of activities.





#### Luke Beardon

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

Luke's Perspectives on Autism blog: blogs.shu.ac.uk/autism

#### Oh dear - poor you and

(possibly) poor him! To me it kind of sounds like a bit of a no-win situation as it currently stands; either you catch whatever it is that he throws, in which case he doesn't get the outcome he desires, or you get stuff broken that you would (I guess) rather remain intact!

Two reasons spring to mind in terms of why he might be going for the breaking option: sensory, and/or release of emotion (sadly, the chances are that he's anxious if the latter is a cause). Either way, he has a high motivation for the 'behaviour' - otherwise why else would he be doing it?!

If it's a sensory experience, never underestimate just what terrific fun smashing things can be; if you don't believe me, go to your local bottle bank and try smashing up a few bottles - it's heavenly! Similarly, if smashing something releases an unwanted emotion, then why would anyone not take the opportunity? So, if there is a strong desire to bash things about, taking the option away from him will likely cause even more problems - so my advice (and allow me to explain in a moment before you decide I'm bonkers) is not just to allow him to break stuff, but *encourage* him to...!!!

Autistic children are not generally stupid. They tend to like to go from A to B in the shortest most convenient manner; so - if you were to give support and space to break things without him having to make the effort himself, you may well find that this is the best option for all involved.

If you go down this road, then what you may find is that all of a sudden, you have the 'control' over what and where the breaking takes place. Say, for example, you invest in some clay pigeons (or you can make your own very cheaply) and design an indoor space in which it is safe to throw them and smash them, then you may be surprised at how quickly he decides to use that very material and area.

Try experimenting with different types of things to smash - in fact, it's well worth noting whether he chooses what to smash or whether it's simply the closest thing to hand; the former might suggest that it's a sensory need, the latter an emotional one.

Either way, finding a type of material that he enjoys smashing that is cheap and convenient is a great idea. Sheets of ice (if you have the freezer space to create them) can be good fun to smash, but you can also experiment with building things to then wreck; towers of Lego<sup>™</sup>, for example, can be mightily fun to throw marbles at until the whole thing collapses (which has the added bonus of being able to be built up again for repeat destruction) and so on...

I'm off now - got myself right into the mood to go and break something - try it, it's fun!

### Do you have a question for Ask the Experts? Email us at editors@aukids.co.uk



Tori Houghton

Speech and Language Therapist, AuKids co-editor and Director of Time Specialist Support

As a Speech and Language Therapist, I'll focus on this issue from a communication perspective. Firstly, try not to despair. Non-verbal kids can come up with very creative ways of interacting and all behaviour is some form of communication. Inconvenient and expensive it may be, but try to think of this as simply a code that needs to be deciphered.

If this isn't a sensory need and is an attempt at communication, your son will care whether you're around or not when he breaks something and will probably wait for your reaction. So – does he do this in front of you or another person who gives a lively and rewarding response (even if it's negative)?

If this is communication, it's either an attempt to interact with you or an attempt to communicate his feelings.

If this is an attempt to try and interact with you, think about how you react and what he likes about it. Do you give him a highly predictable and dramatic response? You've actually become a 'cause and effect' toy! Press your buttons, and you make a predictable noise! Trying to modify your response or even ignoring him (where possible!) might mean that he gets bored and stops.

Also, non-verbal kids tend to enjoy less two-way communication than verbal ones. If breaking things is his main source of interaction with you, think of other ways that will enable him to enjoy your predictable reaction without him having to be this creative!

See AuKids further reading on the right.

If your son is communicating negative feelings, it's a good idea to observe what happens beforehand and see if you can find a pattern. Is he trying to block out sensory confusion or show anxiety at change? Logging the behaviour will help you to spot these patterns and answer his needs. As you continue to support his communication with pictures and signs and his skills develop, you may be able to help him replace the behaviour with a more effective communication technique.

If he is upset, try labelling the emotions he is feeling too, by saying out loud, for instance 'Tim is feeling upset'. The recognition of what they are feeling is sometimes all our kids are looking for. At the same time, bear in mind that when someone is feeling upset or angry, their ability to listen to language and/ or reasoning is compromised, so keep your messages simple.

Finally, a Social Story™ in words and/or pictures could explain why things can't be broken/thrown and what CAN be thrown. You could have a box of balls at the ready to demonstrate!

### **Further Reading**

- 101 games and activities for children with autism by Tara Delaney, published by McGraw-Hill Education 2009.
- Building Bridges through Sensory Integration by Paula Aquilla and Ellen Yack, published by Future Horizons 2015.
- Flying Starts for Unique Children by Adele Devine, published by JKP 2016.
- The Out of Sync Child has Fun by Carol Kranowitz, published by G P Putnam's Sons 2006.

### Further AuKids Reading

- Social Stories Maps of the Social World: Issue 15
- Unlocking the Voice Within: Issue 27
- Play it Their Way: Issue 27
- Conversation without Words: Issue 34
- Putting Parents Back in the Driving Seat: Issue 35





In our fifth birthday issue, we produced the Autism Sundae Dessert, a way of describing autism that all grown-ups could understand. But kids told us that they wanted their version, too! So for kids with autism, their brothers, sisters and friends - this is just for you...

Autism is a bit like an ice-cream sundae. There are lots of different things that go into it. Here's what goes into it:



Everyone who has autism has some trouble with language. We represent this with a scoop of chocolate ice cream. Language isn't just how we speak, it's about hearing and understanding, too. We call this 'language processing'.

A bit like a computer, our brains understand words and their meanings extremely quickly. The autistic brain has a slower processor when it comes to language. This doesn't mean that it's slow at everything, though!

Some people with autism can speak really well, but

still find it difficult to take in lots of spoken information. Some people with autism can't speak at all, but do understand words.

If speaking and understanding is a huge deal in your autism, you get a large scoop of chocolate ice-cream. If it's less of a problem, you get a smaller scoop.



### - Social Communication

Lots of people with autism can speak, but have difficulty understanding meanings. That's because we don't always mean what we say! Sometimes when we joke, we say the opposite of what we really mean. Maybe you can think of an example?

Sometimes, it isn't just words that tell us how people are feeling, but also their faces and

their bodies. Most people are very good at 'reading' not only words, but how others are feeling when they say them. People with autism have trouble with that kind of stuff. It's called 'social communication'.

They might have trouble understanding how they feel and thinking about how others are feeling.

Why does this happen? Imagine that inside most people's brains is a motorway between their eyes and the part of their brain that understands feelings. The two work together really well. For autistic people, it's more like they have a country road between those two places, with a tractor rumbling along it.

It takes a lot of hard work to decide how someone is feeling and why.

They do have exactly the same feelings as everyone else, but they just can't understand them as well.

Stramberry Jce-cream - Rigidity of Thought

A great guy called Tony Attwood explained this really well. He said imagine you are in a huge four-wheel drive car and you hit a problem in the road. That's easy, you'll just steer round it - one way or another you'll still get there! With autistic people, it's as if their thoughts work on train tracks. What happens when a train approaches something on the tracks? It has to brake really suddenly and then it can't move around it.

This is what happens when you have autism. 'Rigid thinking' means that when you expect something to happen in a certain way and it doesn't, it's really stressful. Autistic people like things to stay the same, because their brains struggle to cope with change.

Scoops Change Siges

In some people with autism, rigid thinking (strawberry) is their biggest difficulty. In others, social communication (vanilla) is more difficult. So, you'll get different size scoops from person to person. Scoops can

also change size if someone is stressed out. If they are worried, some of those things might instantly get bigger, causing their autism to be very obvious indeed. It's as if someone has given you a double helping all of a sudden!



Have you ever felt so cold or hungry that you can think of nothing else? When your body is in 'survival' mode, even having a chat with someone can feel like a big effort. For autistic people, differences in the way that their senses work can make them easily uncomfortable. Conversations that seem so quiet to you that they can be ignored may seem loud to some people. Lights that don't bother you could be painful to

them. Material that feels okay against your skin could feel scratchy to them. This is called 'sensory sensitivities' and a lot of autistic people have them

We use chocolate sauce to cover the ice-cream, and it represents 'sensory issues'. When your body is in survival mode, it is difficult to see how well you can talk and understand. We need to understand that things in the room or outdoors may affect how a person acts.

# - Help

If you had an ice cream sundae in front of you and no way of eating it, that would be sad. A spoon helps you to make those scoops smaller as you eat it! The same is true for autism. There are ways that we can help people to work on their language (chocolate), their social skills (vanilla) and their

rigidity

The Flake

Lots of people think that autistic people get angry easily. We represent their anger with a Flake, because it's not actually part

of autism at all. Anger is caused by being

stressed, confused or uncomfortable. It's

just that autistic people have to put up with

those feelings a lot more than the rest of us,

because of the other things that go into the

sundae. With a bit of understanding from

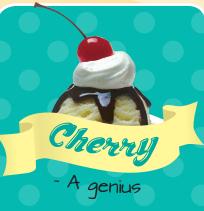
other people, we can take that Flake away.

(strawberry). There are even things that we can do to help them with their sensory sensitivities (chocolate sauce). People called Speech and Language Therapists and Occupational Therapists are sometimes asked to come in and help with these things. But friends can help too – just by being patient!

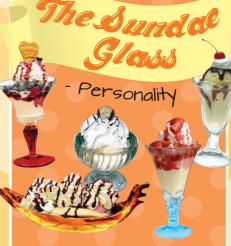
Sprinkles The best bits!

People with autism have different kinds of brains. In some ways this makes things difficult for them. But there are some things that they find a lot easier. Because they tend to learn by looking rather than listening, autistic people have great attention to detail and can often spot things that the rest of us wouldn't notice. They can also have extremely good memories. The straight pathways of their brains means that once they start something, they tend to finish it without getting distracted. When they love something, they become an expert on it, because they don't get bored. They are loyal friends. They say what they mean and they mean what they say. A lot of them (but not all) are great at maths and computina.





Some autistic people have really special skills and they are called 'savants' but you and I would call them geniuses. Because their brains aren't using up a lot of energy in getting on with other people or 'social communication,' all that energy goes into their interest instead. Autism has given us famous scientists such as Isaac Newton, Albert Einstein and Charles Darwin. Have you heard of them?



Because we all have different personalities, autism doesn't seem the same in everybody. The sundae glass makes each ice-cream look different, just like people's personalities. The best we can do is get to know each person with autism, and find out how it affects them.



# A Dozen of Our Best Loved Features

Quite a few of our articles are designed for long-term use and you can access past issues with the help of your username and password. Find them in our archive at www.aukids.co.uk

We often get our inspiration from chatting to each other about living and working with autism. This is where two editors come in handy - we inspire each other with creative ideas. Once we've thought of the subject, we wrap it around a visual theme to make reading about it more memorable.



#### **Jargon Buster** - Issue 13, Autumn 2011

We were fed up of autism jargon, so we wrote this guide. It could have been very boring, but Tori came up with the idea of graffiti and Jo went berserk with the graphics. Jo says: "I had real fun with this spread - creating the graffiti abbreviations and adding big, dripping paint daubs on the flaky, white brick wall in the background."

This article is now available as an A3 poster for £3. Just enquire at admin@aukids.co.uk



### Who Wants to Push the First Domino?

- Issue 16, Summer 2012

We all want change, but we knew that we couldn't expect each reader to become a one-man pressure group. Instead, we gave our readers something that they could leave at places; a tear-out guide giving leisure locations easy tips on how they could become autism-friendly. We mobilized our own little army to instigate change!

We still produce the autism friendly guide as a free A4 PDF and can email it to you if you request it from editors@aukids.co.uk



THIS WOMAN IS A MODEL. THAT IS CREME DE MENTHE SHE'S STIRRING.

#### **Science Fiction & Fact** - Issue 21, Autumn 2013

Some of the so-called 'science' written about autism is actually rubbish. In this feature, we interviewed the authors of The Good and Bad Science of Autism, who trashed some myths for us and provided us with some definitive science about the condition. We finished it off with some amusing photos to highlight that so-called 'experts' sometimes give themselves titles they don't deserve.



#### Make 'Em Lauah - Issue 22, Winter 2014

One afternoon, Tori and Debby were talking about how much progress Debby's twins made when laughter was a part of their learning. Tori talked about some breakthrough moments that she had experienced in schools, where finding out what a child found funny became the key to communicating with them. Laughter, we realized, is an unsung hero and a hugely untapped resource for learning. We hadn't seen this subject tackled elsewhere and Jo's slapstick movie images made it all the merrier.



better than

#### AuKids' Politically Correct **Guide to Clueless Comments** - Issue 25, Autumn 2014

We know that insensitive comments can put a real downer on your day, and so with that in mind we had a good think of all the uneducated and crass openers that could be thrown your way. Then we supplied you with two kinds of answer - a funny, tempting wisecrack and a serious reply. This was AuKids in Big Sister mode, defending the mental well being of our readers and giving them the power of humour to overcome insensitivity. We had a laugh doing this feature, it was quite therapeutic.



#### Maps of the Social World - Issue 15, Spring 2012

Unless you've been on a course, the concept of Social Stories™ can be hard to understand and it can be even trickier to produce them. We decided to condense all you need to know about Social Stories<sup>™</sup> in one place. We used maps as our theme in this guide to writing a Social Story<sup>™</sup>, since we call Social Stories<sup>™</sup> 'Maps of the social world'. There's also a nod to Duran Duran's 7 and the Ragged Tiger album cover.

Colour photocopies of this article are available for just a postage donation, email editors@aukids.co.uk



#### The Search for the Holy Grail - Issue 19, Spring 2013

The way that autism is talked about during a diagnosis HAS to change. If you're presented with autism coupled with the suggestion that all this means is that your child is impaired, then you naturally want to 'fix' them. Many parents spend the early months after diagnosis searching for a 'Holy Grail'. Autism isn't about fixing, though, it's about finding small specific answers to individual challenges whilst cashing in on strengths. There is no Holy Grail - this was a myth that needed debunking, which we did with the help of an Indiana Jones theme. Anything to get a picture of Harrison Ford in the magazine.



# Y - 1 What is Theory of Mind?

Antonia Santa

- Issue 27, Spring 2015

3

Having argued till we were blue in our faces as to whether one famous dress was white and gold or blue and black, Tori and Debby felt this would create the ideal explanation for the Theory of Mind concept. To learn about autism effectively, we need to be able to 'hook' new information onto our own experiences. The dress gave us exactly the demonstration we needed to show how confusing life can be if you assume another person has the same viewpoint as your own. Tori and Debby are still arguing about that dress...





# The Language Layer Cake - Issue 29, Autumn 2015

"When are they going to talk?" parents ask us. It seems that no one adequately explains the development process that a person undergoes before they can develop verbal language. Development charts can be dull, and so inspired by Bake Off, we explained it as a layer cake, using Tori's expertise as a speech and language therapist. Debby pronounces 'layer' in the same way as Mary Berry - without the 'y' -Tori found this hugely amusing and that's why we thought of a layer cake.



### If You're Happy and You Know It, Draw A Face!

Encouraged by the mood diary that we had created to help our autism advocate Tim to gain perspective on his week, we shared the idea with our readers and Jo had some fun with our James Bond joke. Can you make James Bond hold a mood diary? Why, of course...



#### Do You Run A Five **Star Hotel?** - Issue 32, Summer 2016

Debby says: "We're told as parents we've got to work

on our kids' independence, but YOU try it at 7.30am it's not that easy! This article was about how I learnt to do it in the real world, with a cartoon drawn by my brother, Dan. Dan used to cartoon his own birthday and Christmas cards so it was a lovely reminder of my childhood."



#### **The Sixth Sense** Issue 33, Autumn 2016

Quick shout out to Breanne Black, an Occupational Therapist friend of Tori's who has a knack of explaining complex concepts in a simple way. We loved this feature because it explained proprioception without making anyone fall asleep. Her other article on hyper-sensitivity, using different colour telephones, was also inspired ('Getting their Wires Crossed' - Issue 24).

## Behind the Scenes at AuKids...

#### • We never use library photographs for our pictures of children. They are all readers' kids and we don't pose them.

- In this respect David Laslett our photographer is superb; he understands that we like quirky!
- We never Photoshop images of people, but we've played a few tricks on the odd occasion when a seasonal cover photo didn't go our way! For Issue 5, Jo 'invented' some falling autumn leaves and in issue 27, there was still snow on the ground when our spring photo was taken. Jo removed the snow and added crocuses!
- We got extremely giddy when the printer did PERFORATIONS for Issue 16's tear-out autism-

friendly guide. We still get excited about producing an actual magazine...

- After we won the Prolific North Award in 2015, we did really fight over who was to get the award to put in their house, which is why we came up with a jokey photo story about it. In the end, Tim got wooden replicas made for everyone!
- When preparing our Keeping it Together feature about relationships for Issue 7, graphic designer Jo couldn't find the image she wanted... so she and her husband Paul posed for a photograph instead!
- Debby still pronounces 'layer' as 'lair' like Mary Berry.

. . . . . . . . .



Jo Perry is our graphic designer and responsible for the look and feel of AuKids that you love so much. Here's her favourite features:

**Spectrumite Mum's Survival** Kit - Issue 28: I love dressing Debby or Tori up in silly clothes and putting them in a location, in this instance the jungle!

Pass the Pearls - Issue 6: The pearls of wisdom shared by different people are contained in actual pearls. I liked making the photos look aged by adding a sepia tint and adding an old frame to them. I love how you can start reading anywhere on this spread and get lost in a literal treasure trove of knowledge.

The Way to the Land of Nod -Issue 32: I like bringing different people's stories together visually. I wanted to give this spread a soft, glowy, neon, night-time feel to fit with the sleepy theme, I love the way it turned out.

## The Autism Sundae Dessert - Issue 20: I was aiming for

something you might see on a menu in an American diner. I liked adding texture, such as the polka dots inside the boxes and the stripey, solar flare in the background and I had a lot of fun adding the chocolate sauce and sprinkles to the ice cream. I love the way this feature turned out - it looks good enough to eat.



Tim Tuff, an adult with autism, does packing and research for AuKids and gives talks on our behalf. Tim says:

"I liked Seeing the World in a Different Light that AuKids put together with the help of author Olga Bogdashina in Issue 26. It explains quite a lot of things that I struggle with as well as some of my strengths. I think this mentions things that aren't obvious about what we take in -I think people would miss these usually."



We're a leading North West charity offering specialist autism services to people with ASC and their families. From birth right through to adulthood, we have a range of services shaped around you:

- · Special education · Flexible care · Therapy services
- · Family support · Short breaks · Community support

To find out how we can help you, contact us on: t: 0161 283 4848 e: enquiries@togethertrust.org.uk www.togethertrust.org.uk

/TogetherTrust /SupportTogetherTrust



# WAITING FOR THE SIGNAL! Building language with the sound of silence

Speech and Language therapists sometimes use a term called 'sabotage'.

'Sabotage' means that rather than giving your child the thing that they were expecting immediately, you hold back to get some sort of communication signal – whether by gesture or sound.

We prefer to think of this as simply pressing the 'pause' button on our everyday interactions.

# Why do we do it and how does it work?

When a child who hasn't got autism learns to talk, they do quite a few complex things. They listen to others, they copy them and then do it all again in response to praise.

Autistic kids don't learn language by the same methods.

### Why do autistic kids learn language differently?

Firstly, they have difficulty processing language – so listening and learning language delivered at normal speed is not that easy. Copying may also present them with difficulties. Finally, they don't always respond to social rewards.

# What do we do instead?

Young autistic kids often don't recognise the purpose of language, i.e. *in order to get what I want I can use words*. This is because they have difficulty taking another person's perspective. They assume that what's in your head is the same as what's in theirs. Taking someone else's perspective is called Theory of Mind, and kids with autism lack it.

It's our job to show them that we cannot guess what they need –

and that communication is the way to get it!

A child who always gets exactly what they need straight away isn't getting any opportunities to tell you what they want. This is about creating those opportunities and that's where 'our 'pause button' comes in.

## How it works

The first tip is to use a familiar routine, something where you're absolutely certain your child knows what to expect, will recognise something missing and will be familiar with the language around it, even if they are non-verbal.

So, have a think about your regular routines and the language that you use around them. It will be every day simple stuff, like having a breakfast cereal, getting washed and changed, playing a familiar game, or reading a familiar book.

Then, instead of providing the word or object that they're expecting right on cue, just pause a little. See what they do.

Let's make it clear at this point: what we're waiting for is not necessarily words. Lots of non-verbal kids won't be nearly ready for that. We're waiting for signals. You'll know your own child's level – it may be a gesture, a noise, or even a glance. Something intentional. Something to show that they are willing to communicate their needs... something that shows you that they know you are part of this, too.

Simple and subtle signals can be overlooked but they are massively important. They can be built on and they are part of understanding what communication is for.

# Getting it right

How you press the 'pause button' really is significant, says our resident Speech and Language Therapist Tori Houghton. "We don't want to put pressure on our children or wreck their confidence. It's low key waiting. Like leaving a little gap and seeing whether they fill it, rather than a massive expectant pause which puts pressure on them.

"Your tone and manner is all important. You need to be relaxed about this and cool with it if they don't fill in the gap. There's a huge difference between an expectant pause with a facial expression that suggests they HAVE to act and just waiting slightly. Whether they do or don't fill it - that's okay". There are many opportunities during the day where our kids have the knowledge to tell us something.

Co-editor Debby used Alec's favourite Miffy book, where the rhymes were predictable and familiar. When Debby left a gap at the end of the rhyme, Alec filled it with a vocalisation. Gradually that became closer and closer to the actual word. "Alec became aware that I paused and that became a routine in itself," says Debby. "He found it fun to fill in his own bits. If he said 'BAH!' I'd say 'Yes Alec dress!' even though his vocalisation sounded nothing like the word 'dress'. It was his attempt, his signal, and that's what was important".

"There's a great Importance in establishing predictable routines, so that you can break from them to help language," says Tori. "And for verbal children, a pause may be enough to help create more conversation, rather than asking lots of questions".

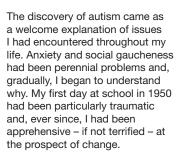
# Try This at Home!

- When you go out, try to avoid immediately offering a coat or shoes. Just wait.
- ★ Get things wrong deliberately. Be a bit silly – go to use your toothbrush for your hair, see them notice it and put words to their gestures or expressions. "Oops! Silly me! I should be using a HAIR brush!"
- ★ Miss out key objects, like 'forgetting' to put a spoon by the cereal and wait for a small signal. Then supply their words as they would say it. 'I need a spoon!'
- ★ During play what would they like you to do? Play dumb until you get a signal, then if they put their hands on yours, or vocalise, put words to what they're trying to say.
- ★ When they sit on a swing just wait a tiny minute. Wait for a signal. "Go? Yes! Go!"
- Establish routines in order to pause them. For instance, start swinging your child – then stop.

# THE INSIDE ANGLE

# An Insight into Anxiety

John Gorham spent his career in the financial services industry. He and his wife Margaret have lived in the Stockport area since 1974, having moved from the South East. John has always suffered from abnormal levels of anxiety and his GP diagnosed him with Asperger Syndrome\* in 2010, after he had retired.



Social deficits and abnormal sensory characteristics help define autism. Nonetheless, a high functioning individual in a cognitive sense has the capacity to devise effective workarounds to help cope in a predominantly neurotypical society. This additional mental processing takes time and effort and can exacerbate the "shutdowns" arising from overload that Tim Tuff described in his Inside Angle article in the Spring 2018 edition. Like Tim, I take steps to avoid full-blown meltdowns.

My attention to detail is a mixed blessing; I have a great aversion to certain sounds and flashing lights which sap me of energy mentally and physically; my colour sight leads to some interesting conversations and I can think of other sensory curiosities that may be related to autism. It is, I perceive, the interaction of these sensory imbalances and low emotional intelligence that drives my difficulties over relationships. unsympathetic reading of my own emotions and, most damagingly, irrational anxieties.

I realise in hindsight that, over the years, I have deployed instinctively a number of strategies to adapt to the world. Structure, stability and predictability are important; careful planning and preparation forestall pitfalls that might complicate life further and smooth major changes; space and solitude (short of loneliness) recharge the batteries.

There has, however, been a price to pay for the relentless effort of having to work out things that come naturally to other people and it really caught up with me in my fifties. Fortuitously, I was offered early retirement at a time when burn-out was starting to kick in. Understanding the implications of autism has helped me to reformulate what's important in life and to devise methods to curb chronic anxiety that threatens to overwhelm. Let me offer a few examples.

### "Structure, stability and predictability are important; careful planning and preparation forestall pitfalls"

**Foreign holidays** Holidays have been an important part of married life with Margaret. Even so, we have identified foreign travel as too stressful for me and Margaret now travels abroad with other companions.

**Social events** I have always been selective and am even more so nowadays. As far as I dare, I avoid most, especially if they are big gatherings. Weddings present delicate issues: it would be wrong not to attend so how do I cope? Go to the ceremony and the feed; avoid the disco like the plague; pace the whole day carefully by allowing plenty of travel time and taking opportunities for time alone; bone up beforehand to minimise the social gaffs.

Small talk I grew up shy and often tongue-tied until, in my thirties, I realised that conversation at business as well as social gatherings was pretty superficial at times but oiled the process. I'm not really into sport and popular entertainment but try to know a little about them.

Driving I somehow passed my test at 18 but rarely drove until I was in my early thirties. Going back to it was fraught until I discovered the then Institute of Advanced Motoring's System programme, which was based on a tightly structured technique used by police drivers. I am still a reluctant driver but it seems to work if I stick to the template and take sensible breaks. I also make good use of my bus pass.

Choose the moment I am uncomfortable in crowds so steer clear of them as much as I can. Being retired, I can usually avoid significant rush hour travel and make trips to the supermarket (armed with a list) at relatively quiet times.

**Technology** I try to keep up with the modern tools of living, albeit it's a battle. Among other things, word processing, e-mails and video are handy ways of keeping in touch with people without the hassle of physical meetings.

Keep learning I've never found classroom tuition particularly effective and often found myself on a different wavelength to a teacher. I got through most of my professional examinations by distance learning and private study, and I gain much satisfaction from working out things for myself rather than their being presented on a plate. I suspect I'm a 'visual learner' and I only wish co-editor Debby's article on social skills "Living by The Rule of Thumb" (Spring 2018 edition) had been around when I was growing up! At any rate, Aukids magazine has become part of my regular reading in a quest for new insights into the condition.

To summarise, it's important to recognise that autistic children will have increased levels of anxiety – but by a combination of lifestyle and management, you can reduce this, which in turn will have an effect on their ability to adapt better socially. It will stand them in good stead for life later on.



# Home Is Where the 'Hortlands' Is

By Debby Elley

When people ask me 'Did you have a nice holiday?' and I reply 'Great, thanks', I am usually lying through my teeth.

What I actually mean is: 'I spent half of it trying to prevent a calamitous breakage in our holiday let and half of it in a state of SAS-like alertness. I'm actually more in need of respite than before we left.'

It's relatively easy for other parents to get relaxation time. Go abroad. Join kids' holiday club. Job done.

It isn't as simple for families like ours, where lack of Wi-Fi could cause an international incident and anything that looks decorative will probably be gleefully dropped from a height.

I'd just about accepted that the word 'holiday' was basically a contradiction in terms when I happened across Hartlands in the Isle of Wight, a holiday centre designed for autism families. It was the first time we'd gone for anything 'specialist' but co-editor Tori and I felt that for the sake of our readers, my family needed to check it out.

With one non-verbal twin who'd give a bull in a china shop a run for its money, and one verbal one who is surgically connected to the internet

# Holiday Tips From AuKids

- Cut down on driving time choose a base where attractions are less than an hour away.
- Look up attractions beforehand and check out quiet times; book ahead.
- Pack your DLA (Disability Living Allowance) letter to get into places at a discount and to get 'exit passes' for rides.
- Plan dinners out in advance. Look up the menu, print it off and book ahead.
- Buy a Radar key (Amazon or Ebay) so that you can access disabled toilets anywhere.
- Prepare a holiday guide, with photographs and facts for your child. Include reassurance about the familiar things (and people) that will still be around them.
- A beach tent with favourite items can become a haven when in unfamiliar surroundings.
- Holiday advice from the National Autistic Society can be found at: www.autism.org.uk/about/family-life/ holidays-trips/preparation.aspx

at all times, we were well placed to test its suitability for other families.

I'm happy to say, it was well worth the trip. Just check out the top of this page. It doesn't say ADVERTISING PROMOTION. What you're about to hear is impartial. I can't help it if what we experienced was damn near perfect.

Owners Colin and Elaine Pratt set up Spectrum Breaks to run Hartlands after enduring years of stressful holidays. Their son Thomas, now 19, was diagnosed at three with severe autism and epilepsy following brain surgery.

Not content with simply wishing something would change, the couple surrendered a comfortable existence in London's Biggin Hill, sold their home and used their life savings to purchase Hartlands, a derelict former hotel in

Shanklin on the Isle of Wight. Over the next five years, they set about converting it into three bespoke holiday apartments (now four) set inside a tailor-made autism complex.

Professional input was on hand in the form of a team of willing experts, including Dr Viv Hinchcliffe, a leading specialist in setting up schools for special needs children, and Dr Elaine Hughes,

a Consultant Paediatric Neurologist at Kings College Hospital. Inspired by the aims of the couple, warm-hearted volunteers also helped with this huge conversion project and Hartlands welcomed its first guests in 2016.

We stayed in the Isaac Suite, a large threebedroomed apartment that sleeps six. The master bedroom's spacious en suite doubled as the bathroom and both children's bedrooms included an en suite with shower. With a toilet per twin, we were already in heaven.

On first appearance, our apartment

resembled a smart, clean, contemporary holiday home. Lurking beneath the surface, however, was formidable attention to detail for comfort and safety.

The couple had reckoned that any apartment safe enough for Thomas would suit most needs. Their plans, therefore, had taken into consideration anything that could be escaped from,



broken. Through numerous smart and careful adaptions, the single-floor apartments relieve parents of a multitude of anxious moments.

meddled with or

Our front and patio doors, for example, were fitted with an alert function in case anyone fancied popping out without telling us (Alec). It had calm and sensory lighting, with no mess fittings and automatic sensors in the hallway. Dozens of safety features included hob and oven locks, a locked knife block and window security. Walk-in showers were operated with a simple on-off switch and basic temperature control, with the upper limit set to prevent scalding. Even sharp-edged bathroom mirrors were protected with rubber corners.

Wandering around with my usual eye for



"Colin and Elaine's passion for providing genuine respite is evident in every corner of this relaxing retreat."



potential disaster, I could find nothing to worry about. Until I stayed here, I don't think I realised how much of the time I spent on holiday with one ear cocked for signs of trouble. My ears felt surprisingly relaxed.

The bedrooms' thoughtful touches included waterproof sheets and black-out curtains, plus colour changing night lights. There was a distinct lack of breakable objects, too. No little boats with delicate masts, no faffy little furnishings to get ruined. Lamps had heavy bases and wall decorations were sturdy canvasses depicting calming, natural scenes. Even the paint colours had been selected for a soothing effect.

Downstairs in the public areas of the centre, the highlight of Hartlands is its giant sensory room, full of light up and tactile toys. Its restful design inspired by the ocean, the room's colour changing ceiling lights added to the atmosphere. Alec immediately immersed himself in exploration and was so well occupied that his repetitive twiddling reduced markedly over the week. A little beach hut in one corner of the sensory room provided gentle natural sounds. A table tennis table inside the sensory room and a lounge area down a few steps made for great chill out times for the adults even in the presence of our youngsters.

Hartlands has a projector screen linked to a computer, so that guests can select from a huge range of kids' TV series and films. In the same area is a computer room, where Bobby played each evening without us, as he would do at home. A few autistic kids from other families joined him, so it became a great social focus.

Across the corridor was a music room with a huge range of instruments, with guests encouraged to give anything they liked a go. The room led to a separate games room with pool and snooker; a window separated the two areas so that you could watch your kids while potting the white (in my case). In the event, Alec took a decided interest in dunking snooker balls down the corner pockets and listening for rolling sounds beneath the table. No-one minded, they're used to it.

The ground floor included an art room for creative types and a heated (to 34 degrees) salt water indoor pool, which we happily exploited during our stay. Alec's one of those kids who enjoys swallowing chlorinated water for a laugh, so this was another welcome change. This works on a booking system, so we had the pool all to ourselves. One thing that could improve the pool would be a changing area or screen – darting up to your room with a towel round you could get a little chilly in winter as the adjoining corridor isn't heated.

What I love about Hartlands is that none of the original vision has been lost in translation. Colin and Elaine's passion for providing genuine respite is evident in every corner of this relaxing retreat.

After an extensive search of the UK involving the TV programme Escape to the Country, Colin and Elaine chose The Isle of Wight as the ideal getaway for autism families. For this reason, I'd highly recommend it even if you don't end up staying at Hartlands.

Not only does the island have numerous sand and shingle beaches, but it is also small (covering 150 square miles), quiet and safe. Pretty much every attraction is within a half hour drive, which saved on planning and travel. Even in the bad weather we experienced, there was a huge amount to keep us busy. Attraction staff were noticeably tolerant and flexible, too.

Bobby finished the holiday by saying that he'd like to come here again – I nearly fainted. Alec, meanwhile, told his teachers (through the use of symbols) that he had stayed in a castle. As far as he was concerned, that huge, delightful centre was ALL for him.

And it certainly felt that way to us, too.

### Further Information

- For 7 nights, the price for an apartment sleeping six ranges from £1,035 off peak to £1,554 during peak season.
- For 7 nights, the apartment sleeping eight (Vincent) ranges from £1,290 off peak to £1,939 during peak season.
- For 7 nights, the apartment sleeping three (Albert's), ranges from £772.50 off peak to £1,162 during peak season.
- Off-peak, you can choose a long weekend break, a shorter mid-week trip, or full week+.

### Holiday Grants

- www.familyfund.org.uk (grants are dependent on income).
- www.trefoil.org.uk/applications/ lilias-finlay-holiday-fund
- 💙 www.turn2us.org.uk
- Direct Payments and Personal Independent Payments can sometimes be used for this kind of respite – check with your local authority.

### More Autism-Specific Places

Other autism holiday centres include The Thomas Centre in Lincolnshire at thethomascentre.co.uk and Leafyfields Glamping in Devon, which is a new specialist camping site for autism – look up www.leafyfieldsglamping.com

Autism on the Seas is an American company providing specialist cruises www.autismontheseas.com

Have you visited somewhere autism friendly this summer? Write and tell us!

- Spectrum Breaks enjoys a discounted rate with Red Funnel ferries, and can book for its guests, including priority boarding. The discounted return ferry ticket was £72.02 for our family of four at Easter, but prices vary according to the time of year. The ferry trip from Southampton-Cowes takes an hour.
- Shanklin is less than a 30-minute drive from the ferry port.
- Hartlands welcomes off peak wholecentre bookings from schools and support organisations.

Colin and Elaine are offering AuKids subscribers a special discount code, entitling you to 5% off your holiday with them! E-mail editors@aukids.co.uk with your AuKids username and password to receive your discount code. To book, go to www.spectrumbreaks.co.uk, e-mail support@spectrumbreaks.co.uk or call 01983 864885/07973 174 682.





# The Last Word

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

# Climbing Mountains One Step at a Time

Since we started writing AuKids ten years ago, Bobby has turned from four to 14. Alongside this evolution comes new challenges.

As adults, we know that independence isn't something that happens suddenly. I realised that Bobby's ideas about this were different, however, when I asked him if he'd help me with the cooking. He panicked. "Am I an adult now? Do I have to live on my own?"

Bobby seemed to think that the bridge from childhood to adulthood was like crossing a border into a foreign land. I had to explain that independence is simply a gradual slope, to be walked up slowly and one step at a time.

For non-autistic kids, independence happens naturally; it's something that they crave.

I remember clearly the moment in 1986 when I spotted my dad standing in the middle of a party at midnight, searching for me. I could be found hiding behind an alcoholic drink, wishing fervently that the floor would swallow me up. As I realised in horror that a parent was in the room, I thought: *'From now on, my brother collects me'*. My brother wore a leather jacket. He had cred.

Our autistic kids don't crave independence, though. Quite the opposite - they want everything to stay the same. Tim Tuff told me that the experience of being a 'teenager' only seemed to happen to other people. He didn't rebel, he didn't fill his head with girlfriends and parties, or argue with his mum. During this time, undistracted by dreams of independence, he had a distinct advantage at school. Later, he found independence to be a necessity – but it was exactly that. He actively had to learn it. Aware of this, I've started to introduce independence by stealth. In my view, you can't start this early enough. If our kids realise from an early age that learning to do things on their own is part of growing, independence doesn't seem so daunting. Wish I'd started a bit sooner, to be honest.

In town, I began by allowing Bobby to go to the gaming store CEX on his own (it bores me rigid anyway), whilst I watched him from the subtle vantage point of a café directly opposite. Next, he could negotiate the pedestrianised area between CEX and GAME without calamity. At first, I'd follow him at a discreet distance, feeling the need to wear a trench coat and dark glasses. Finally, as my trust in him built, Bobby progressed to walking up the road and crossing a small street to reach the retro computer store, where we know the owner by name (Hi, Dean).

Locally, Bobby has practised walking to the park and back, which is just a road away. I followed him a few times at a distance and became convinced he was ready. Beforehand, I give him direct instructions about talking to others and watching



HERE'S ONE I MADE EARLIER: AuKids has seen our twins grow up

for cars, and texting me when he's there. We both wandered to that park earlier this week after Bobby announced that there was a Pokemon raid there. Once



Living with autism isn't

easy. But finding out all

about it should be.

there, we bumped into about 15 Pokemon fans who had shown up for the same event. They were from the local Pokemon group, of varying ages and immediately welcoming. "Come and join us! That group's raid is just starting over there!"



They were shouting instructions to each other in some sort of foreign dialect. We stood with a few older guys, alongside a couple sitting in a sort of Scooby Doo van. A young chap lent on the van window, relaying messages.

autismlinks

I discovered that the foreign dialect was Pokemonese.

The raid started, and Bobby magically started conversing. I experienced a strange sensation. Looking over his shoulder, for once I was the outsider. Bobby was clearly in his comfort zone, gliding effortlessly through the battle chat.

The club members asked him to join and since they often do 'raids' at the park, I had a delightful glimpse of an independent social life for him. Well, after I've accompanied him for a bit. It was as if I had been rewarded by the leap of faith that I'd taken in encouraging his independence, with a little pot of gold at the end of the rainbow.

One small step for Bobby, one giant leap for Spectrumite Mum.

P.S. By the way, a great book on helping your autistic kids to achieve independence is The Loving Push, by Temple Grandin and Debra Moore, published in 2015 by Future Horizons.









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