



# Aukids®

Issue 42  
Winter 2019

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# Letter from the Editors

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We are a charity that specialise in technology for disabled people. Through training & assistive technology, we help disabled people speak, live independently, control their environment & have fun! We have a range of free services at our centre, get in touch to book an assessment, book onto our disabled gaming sessions or arrange a technology workshop!



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Happy New Year from all of us at AuKids! We are delighted to have you with us for another year of fun and friendly practical autism advice.

This issue is the answer to life, the universe and everything. Co-editor Debby's son Bobby pointed this out on seeing that it was Number 42. If you haven't read *The Hitchhiker's Guide to the Galaxy*, disregard that last sentence and assume we're a bit nuts.

Let us start with the advice we always share in January. Keep New Year's resolutions nice and flexible. It's great to have targets to aim for with your family. Small ones are the best – those you know you can reach with a little stretch. If a strategy isn't working, take a break from it, don't be too hard on yourself or your child. January 1<sup>st</sup> isn't necessarily the perfect time, it's just a date after all. Our recommendation is not to resolve to 'fix' issues, but to choose to be better informed and in a better position to tackle them. It's a more successful approach to create 'finding out' goals for yourself. The better your knowledge, the more you'll be in a position to devise suitable strategies.

Choose just a few things to tackle that will make a real difference to the quality of your child's life and to your family's, too. If you become stuck, that's what we're here for! Just write to [editors@aukids.co.uk](mailto:editors@aukids.co.uk) and ask us for a feature. Don't forget that our archive is packed with great advice, too. If you didn't receive our archive guide with Issue 40, just write to us and we'll be happy to send you a PDF.

If you love AuKids, remember that as a social enterprise we need all the

help we can get! Fundraising and donations make such a difference to us. We've already had a group offer to complete the Manchester Run for us and we're always humbled by our readers' offers of help. We don't survive on advertising – we want you to enjoy solid editorial, broken up only by useful adverts on products and services we have researched ourselves (nothing dodgy gets past us). For that reason, we are always finding new ways of raising cash.

Looking to help us and your organisation at the same time? The AuKids editors provide fun training on autism within the North West. Plus, Debby presents the story behind her 2018 book *15 Things They Forgot To Tell You About Autism*. Want to hear personal experiences of autism? Our volunteer Tim Tuff shares some deep insights into autism with his talk *Jam on a Marmalade Day*. Please contact us at [editors@aukids.co.uk](mailto:editors@aukids.co.uk) for price details and to book.

Finally, we are happy to welcome new advertisers Bridges in Social Understanding. Bridges offers a unique online course in social skills for youngsters with autism. The course is written for parents or teachers, with interactive resources included to help you teach those precious skills to your children. Having read a course section, we were rather impressed and wanted to help promote them.

We hope you enjoy Issue 42! Even if it's not the answer to life, the universe and everything, it's a start...

*Tori & Debby*

## Got a Child With Autism? You need



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EDITORS: Debby Elley (Executive Editor) and Tori Houghton (Associate Editor)

STAFF WRITER: Mark Haworth

RESEARCH AND ADVOCACY: Tim Tuff

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## Cover Star

### Julia and her Daughter Isla

My name is Julia Maunder and I have two little girls Merrily (9) and Isla (8). Isla was diagnosed with autism at the age of three. Before I had children I worked in the charity arm of a large pet supplies retailer. However after having two children so close together we found childcare too expensive and I had to give up work. Also with Isla's needs I wanted to be at home to attend the many appointments she had and to ensure she was getting all the support and input she needed.

For me, life at home with two small children was very isolating. The majority of my friends worked and our families are not local. My amazing Portage worker told me about a charity local to me called Independent Options Children and Family Centre in Hazel Grove, Stockport, that provided sessions for children with additional needs and support for their families. Little did I know that it would be the start of a career path for me.

We attended the centre for a few years and enjoyed the sessions put on by the team. We got to know many of the other families and made some new friendships. When Isla started school, I heard about a job opening as a part-time play leader at the centre. I knew immediately it would be something I would love to do.

I have been working there for nearly three years now and recently took on the role of centre manager. I love being able to offer support to the children and their families who attend. My job is part of our family, the girls love coming to the centre and my husband is also on the Board of Trustees. Isla has opened up a whole new world for us all.

### ..... FACTFILE .....



**Isla loves:** Pizza Hut, Minecraft, her pet millipede 'Black Rampage' (yes that is the actual name she chose for her millipede!)



**Isla's not so keen on:** Loud talking, being asked questions, things being unfair and something called 'stetchweed' - we've never figured out what this is!



Isla, Andy, Julia and Merrily

## IS THIS THE MOST AUTISM-FRIENDLY RESTAURANT IN THE COUNTRY?



**PRICELESS PIZZERIA:** San Rocco manager Mark Waine (with AuKids certificate) with reader Lee Sweeney (standing - fourth left), his wife Nicola and son Taylor (far left), Debby's sons Bobby (with Pikachu) and Alec (ear defenders), with Debby, Tori and her son Remy and staff from the restaurant.

Recently, we received this letter:

Dear AuKids,

I wanted to get in touch to tell you about the amazing efforts made by a restaurant in Ashton-Under-Lyne to make their environment autism friendly.

From the moment we first walked into San Rocco and were greeted by the manager Mark Waine, we knew this was a special place. He made such a lovely fuss of our autistic son, Taylor. I explained that he couldn't speak and he had autism. Mark said "Well, he can hear me, can't he?" and myself and my wife looked at each other as if to say 'He is right, he can'.

Nothing has ever been too much trouble, so the table is clear when we sit down - no glassware, no cutlery or condiments as Taylor also has pica, so everything goes straight into his mouth. One day Mark saw us using the picture cards we had to help Taylor choose his meal and he said he had come up with an idea to make a picture menu for children and adults with autism and learning difficulties and wanted to run the idea past us. I looked at my wife and she had a tear rolling down her cheek, she was so overwhelmed with the idea, as was I. Mark enlisted the help of a speech and language therapist to create the menu and it's proved to be very successful. Taylor loves it and other families living with autism have come from far and wide to use the menu, it's amazing.

Just recently we found out that at staff meetings it's discussed how to make people in our situation feel welcome and at ease

and for staff to ask what they can do to help make it an enjoyable experience.

They have also held charity events at the restaurant to raise awareness of autism.

The staff all work so hard towards making eating out inclusive for all.

We are so thankful that San Rocco has given our family and others a social life.

Kind regards  
Lee Sweeney.

We were so moved by this letter that we decided to check out San Rocco for ourselves. Debby brought along her twins Bobby and Alec and Tori accompanied her with her son, Remy. Two teens with autism and a toddler!

The atmosphere of friendliness and the staff's flexibility and compassion were outstanding. The manager even warned us that they were going to be playing 'Happy Birthday' quite loudly for a large party on another table. Were we okay with that? And yes - the food was delicious too!

At the end of the meal, our undercover gang surprised the San Rocco team by presenting them with an 'AuKids autism friendly' certificate. Lee, Nicola and their son Taylor were also there for the presentation.

Manager Mark Waine was modest about what they do at San Rocco: "I see kids as a joy, so that's what the restaurant is all about. Families can't stay home all the time - so, we do our best!"

To find out more about this restaurant, go to [www.sanrocco.co.uk/san-rocco](http://www.sanrocco.co.uk/san-rocco)

Check out our Home page at [www.aukids.co.uk](http://www.aukids.co.uk) for our poster with tips for making your establishment autism friendly.

**WIN  
a Copy!**



**BOOK**

**Therapeutic Adventures with Autistic Children - Connecting through Movement, Play and Creativity**

By Jonas Torrance  
Published by Jessica Kingsley  
£14.99 • ISBN: 9781785924552

The title perhaps suggests that this is a therapy guide. Really, it should be called Diaries of an Amazing Therapist, as that's essentially what this is.

The author is a registered Dance Movement Psychotherapist and behaviour consultant with 35 years' experience, but reading the blurb on him may suggest that this book has a narrower remit than it does. This isn't about dance therapy. It isn't a teaching guide. It's my favourite kind of title, recalling in 13 hugely varied true-life stories how Jonas has achieved breakthroughs with his young autistic clients.

None of these are miraculous tales of sudden epiphany. What they describe is the gradual process of observation, patience and reflection leading to creative interventions, many but not all involving some form of movement or the outdoors. The outdoor work often reminds me of how 'hemmed in' autistic children can feel, and the relief to be found in the calm and space of nature.

The author's ability to be in tune with these youngsters is down to a central philosophy on his part – that no child is beyond our reach as long as we try to read what their behaviour is telling us about them. It's perhaps unsurprising that under the veil of many a difficult behaviour lies anxiety and uncertainty.

Each chapter is rounded off by simple and practical suggestions for anyone who finds themselves facing a child with similar issues. And boy we have issues, including violence and destruction. Jonas often seems to be flown in where others are at the end of their tether!

If there is any book to show that one size DOESN'T fit all when it comes to intervention, then this is it. The real importance of this book is not down to a raft of strategies, but the approach that the therapist takes in creating them.

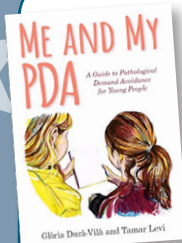
Debby Elley, Co-editor AuKids.

**WIN**

**AuKids has two copies of Therapeutic Adventures with Autistic Children to giveaway**

Email your name and address to [competitions@aukids.co.uk](mailto:competitions@aukids.co.uk) with Jonas in the subject header, no later than February 28<sup>th</sup> 2019. By entering this competition you give permission to AuKids to pass on your address to the publisher so that they can send you your prize. Entrants must be 18 or over. Good luck!

# Reviews & Prizes



**BOOK**

**Me and My PDA - A Guide to Pathological Demand Avoidance for Young People**

By Glòria Durà-Vilà and Tamar Levi  
Published by Jessica Kingsley  
£14.99 • ISBN: 9781785924651

This book dedicates itself to a condition within autism known as PDA (Pathological Demand Avoidance). Not yet recognised within the formal diagnostic criteria for autism, it's certainly hit some controversy. However, it refers to a sub-category of people with autism whose rigidity is so severe that it causes them intense and crippling anxiety when faced with any demands or unexpected changes. In addition, many tend to have a preference for expressing themselves through mimicry and fantasy and have other traits that are not always associated with autism.

Glòria Durà-Vilà, a consultant child and adolescent psychiatrist with an expertise in autism, has constructed this helpful interactive workbook for children with the aid of Tamar Levi's lovely illustrations.

What I like about this book is that it helps any child to build up a picture of their individual needs, stressing that not all children have difficulty with the same things. It summarises common difficulties recognised in PDA, before asking the young reader to reflect on

how much each affects them, and how.

Readers are encouraged to express themselves with words or drawings inside the book. The second half of the guide is dedicated to a range of strategies that could help with each difficulty, using strengths such as imagination to combat challenges. Its tone is deeply sympathetic and gentle and will help any child reading it to explore who they are, where they struggle and above all to accept themselves. Even the fact that it's been written at all 'just for kids like you' will generate a sense of belonging.

As a parent, I'd be inclined to avoid tackling this book all in one go. I'd recommend adults read it first, so that you'll be able to identify when it gets tough, even skipping to specific strategies early if you need to (Page 65!).

There's plenty of space at the end of the book for youngsters to clearly identify their own way forward for each difficulty, and so as well as reminding children of their own inner resources, it'll provide a good comprehensive record for any teacher or carer who'd like a snapshot of the young person's needs.

If you like the look of this book, the same authors previously created *My Autism Book: A Child's Guide to their Autism Spectrum Diagnosis*, through the same publisher, which has been well received.

By Debby Elley  
Co-editor AuKids



**BOOK**

**My Special Brother Bo**  
Written by Britt E. Collins & illustrated by Brittany Bone-Roth

Published by Future Horizons  
£10.50 • ISBN: 9781941765920

This book is about a seven year-old girl who has an autistic brother called Bo. The author has spent many, many years studying and working with children with lots of different conditions. It talks about what Bo can do and what he cannot do. Also, it talks about how Bo learns new things differently. It says that sometimes Lucy can't go places she wants to as it might upset her brother and it makes her sad at times, but she understands eventually

because she loves her brother and wants him to be happy.

I really liked the book, the pictures were great and it was nice and easy to understand. The book has helped me understand that sometimes I can't do things as it causes my brothers issues and I don't want them to be unhappy, so I have to be patient.

This will help other children - especially ones who have just found out that their brother or sister is autistic. It also helps because it talks about how Bo has to go to different hospital appointments often like speech and language to learn things.

Also, one last thing. Autism is cool.

By AuKids reporter  
Izzy Toman, aged 7,  
(sister to two brothers with autism).





### BOOK

#### Simon and the Magic Drums

By Rebecca Wright

Illustrated by Sally Smoerville-Woodiwis

Published by Grosvenor House

£5.99 • ISBN: 9781786233752

Simon and the Magic Drums is a lovely fable written by first-time author Rebecca Wright.

This is self-published by Grosvenor House Publishing, and for that reason may not get the attention it deserves, but in just 48 pages it's a valuable and memorable tale for any autistic child who's finding trouble fitting in.

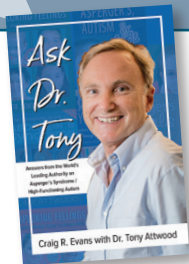
Unable to express himself fully with language, young Simon struggles to fit in and spends his time avoiding social situations. Then one day, when trying to escape from his classroom, he finds an abandoned music room. Inside it is a magic drum kit. The drums, each with a distinctive personality of their own, make it their mission to help Simon to find his true voice; that

passion for something that will help him to fully express himself and to shine.

Aimed at ages 7-11, this book's laudable aim is to help children to recognise that there is more than one way of expressing themselves - and that finding your own voice doesn't necessarily mean being eloquent with language.

The author is a teacher specialising in singing, acting and dance. Her own son has autism and Rebecca is currently running workshops on 'finding your voice' for schools. To find out about these workshops, go to [www.simonandthemagicdrums.com](http://www.simonandthemagicdrums.com) or e-mail [beckybook@live.com](mailto:beckybook@live.com)

By Debby Elley  
Co-editor AuKids



### BOOK

#### Ask Dr. Tony

By Craig R. Evans & Dr. Tony Attwood

Published by Future Horizons

£19.59 • ISBN: 9781941765807

In 2006, Craig Evans started a website called Autism Hangout ([www.autismhangout.com](http://www.autismhangout.com)). Autism Hangout was a forum where autism 'thought leaders' supplied answers, advice and encouragement to families and individuals.

Through it, Craig became well acquainted with Dr Tony Attwood, a leading psychologist, speaker and author. In 2009, they launched Ask Dr Tony, a tremendously successful online show at the same website. Members of the Autism Hangout forum posed questions and Tony answered them in more than 40 shows that remain online. After a brief break, Tony and Craig restarted Ask Dr Tony in 2017, but were keen to share Tony's earlier interviews in a book. This is that book.

By the very nature of the forum on which this is based, the topics vary wildly. Some relate to young, non-verbal children with autism. Some relate to marriages in which one partner

is on the spectrum. There are sections on work, bullying and anxiety...It's quite a treasure trove of subject matter.

For anyone interested in all matters autism-related, this really gives you a sense of where we are up to with our understanding of autism. Tony's advice is both direct and balanced and his 'voice' always imbued with a deep respect for others. What comes across more strongly than anything is the need for better education to reduce the harmful and lasting side-effects of being misunderstood.

Tony also provides readers with some good pointers on further reading, valuable websites and even individuals to approach. More than anything, this has pointed me to the original website on which it's based - and it's gained another fan!

By Debby Elley  
Co-editor AuKids

# The Perfect Tag Team!

Clare and Deborah of Orkid Ideas have developed some fabulous anxiety busting tools to add to their popular TomTag range. Clare's son, Tomas, who has autism, was again the inspiration behind the new products. As Clare explains: "Anxiety is the greatest source of stress for Tomas. Being highly anxious most of the time is emotionally and physically exhausting for him, so we started developing our TomTag visual supports to help Tomas and other children like him to deal with their anxieties."

The **TomTag Manage my Feelings** kit not only helps children to understand and communicate their feelings and emotions but it also includes symbols that can suggest useful coping and calming strategies to reduce the intensity and frequency of feeling anxious.

"When we saw just how popular this kit was, we really wanted to offer our customers even more support in this area," says Deborah. "That's when we hit upon the idea for the **TomTag Feelings Notebook** and **Feelings Thermometer Tag**."

The notebook is a place for children to write, draw or use stickers to record their feelings and worries or things that have happened. This then helps the child, their parents or teachers spot anxiety or behaviour triggers and can also be a great way to manage home-school communication.

The **TomTag Share How I Feel** tag uses a thermometer-style sequence of six feelings faces to help identify, express and share feelings and is an ideal accompaniment to the kit and notebook but works equally well just on its own.

Visit [www.orkidideas.com](http://www.orkidideas.com) for more information about all these products, where you can also get a free download with advice and ideas on how to use the feelings thermometer.



## Win a TomTag Feelings Bundle!

Orkid Ideas are giving one lucky AuKids reader the chance to win the complete TomTag Feelings bundle, worth £32.50:

- I Can Do It - manage my feelings kit
- My TomTag Feelings Notebook
- I Can Do It - share how I feel tag
- One runner-up will also receive a TomTag I Can Do It, share how I feel tag

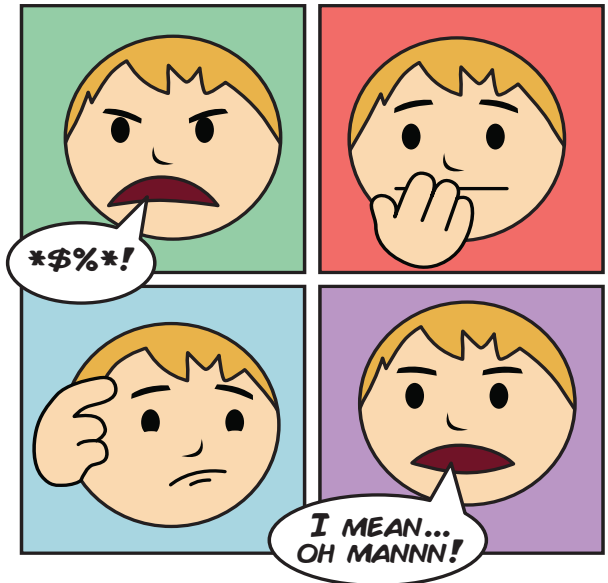
Want to win? Visit Orkid Ideas website and tell us something that Tomas loves to do. Send your reply to [competitions@aukids.co.uk](mailto:competitions@aukids.co.uk) or write to AuKids, PO Box 259, Cheadle, Cheshire, SK8 9BE no later than February 28<sup>th</sup>.

Competition open to over 18s only. By entering this competition you consent to AuKids forwarding your name and address to Orkid Ideas so that they can send you your prize. No cash alternative. Good luck!





“ Our seven year-old son has started swearing... a lot! He used to swear when he was surprised, instead of a simple ‘Oh, wow!’ - more for shock and reaction than anything else. But he is doing it increasingly when frustrated and has now started swearing in school. We’re not sure if his colourful language is a phase or a tic (sounds like Tourette’s at times!) but we’re struggling to get through to him. ”



**Debby Elley**  
Co-editor of  
AuKids magazine

When autistic kids first come across swear words they suddenly learn the power of them and it's quite exciting. What they don't really understand is the social implications of using them, and they can quickly get into the habit. Unchecked, that habit can even become a form of stimming (self-stimulation). People tend to think of stimming as just repetitive movements but it can be words, too. Autistic people sometimes swear when they are using echolalia too (repeating something they've heard elsewhere again and again, sometimes to help them express their own feelings but sometimes just for entertainment).

If your son is consciously swearing for effect, a Social Story™ could be useful, to encourage him to be aware of how his words create feelings in

other people. See AuKids Issue 15 for how to write a Social Story™, or write to us at [admin@aukids.co.uk](mailto:admin@aukids.co.uk) if you'd like us to write one for you (there's a small charge).

I'd also suggest something that one of our experts, Dr Heather MacKenzie, urged me to try - and it worked!

Once my son Bobby understood that it wasn't always desirable to say a swear word, he told me that when they were in his head it was hard to keep them unspoken. He had to get them out whether he wanted to or not!

So, instead of talking about HIM swearing, we distanced him from 'the swears' and observed (calmly) that we had a problem with 'the swears' escaping his brain.

I got an empty swear jar and whenever he felt like swearing, he'd take an imaginary scoop along his forehead 'taking the swears from his brain' and put them in the jar. We made it into a game 'Oops! A swear is escaping! Quick - scoop it up and throw in the jar!' It worked!

For swearing that has become stimming or echolalic, this is slightly more problematic because it's sub-conscious. But one of the things we'd suggest is telling school that these words are just sounds to your son and aren't meant aggressively. Parents can be devastated about inappropriate echolalia, but it's not your fault and it's not his, either!



**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](http://blogs.shu.ac.uk/autism)

Ok, well the childish part of me (which clearly takes up the majority of my brain) instantly high fives the little chap and whole-heartedly chimes, 'yeah - dude, swearing is fun, it's the bomb'; I know it's not 'big or clever' but then neither am I...!!! And yet - in this case, I am very hesitant to do so, as those three (possibly seemingly innocuous) words 'increasingly when frustrated' may tell a dark tale.

If - and I am venturing into guesswork here, but based on the question it seems fair - if the swearing is a direct result of frustration then this could be a classic case of communication; he is communicating that he's stressed. If this is, in fact, the case, then reducing the swearing - whatever the means - is not what is needed. That would simply remove his (quite possibly effective) way of telling the world that he has reached his frustration threshold. To enforce this with a child who (by definition) has issues with communication could be devastating. Maybe it's more a case of trying to work out what is causing the frustration in the first instance - and working on that?

However, I also recognise that kids aged seven are frowned upon when using swear words - however 'appropriate' it actually might be; so, if he really is swearing out of frustration then it could be that a direct swap of words/actions between swearing and (for example) showing a red card to the teacher to communicate that he's at the end of his tether would make everyone happy - he still gets to communicate his needs while not upsetting those around him.



**Greg Loynes**

Head of Admissions, Transitions and Outreach (Inscape House - a school for children with autism run by the Together Trust).

OK, so here's the thing, most of us swear...even teachers! I have even shouted the F word in the lunch hall, in front of all our students!

I'd better put that fact into context.....One of my then pupils had been taking something electrical apart and had harvested two extremely strong magnets from said item. We had been experimenting with them all morning, amazed at how they could still attract each other, even through the desks! Well, Matt walked past me and obviously wondered if they would attract each other through my earlobe and, without warning, tested the theory...OMG it hurt!!! Hence the expletive...and the following stunned silence, followed by uncontrollable laughter in the hall!

Being a teacher of kids with autism, I regularly use this example to help explain when it is ok (or not) to swear....

- During a Maths test at the teacher? **No.**
- In the supermarket? **Probably still a no but see my example above!**
- As an older teenager when with friends, out of earshot of adults? **Probably yes....?**

This leads us to exploring which words we can use and when. It very much depends on the context as well as the beliefs and values of the audience....no wonder kids with autism struggle with swearing appropriately!

It is important that everyone working with a young person

about swearing agrees on what constitutes a swear word..... consistency is always important with anything autism-related.

This leads me to my favourite activity ever!

'OK class, tell me all the swear words you know and I will write them on the whiteboard....' I generally increase my vocabulary at this point! Once every rude word we know has been noted, we colour code them.

**GREEN**  
= mild expletive

**AMBER**  
= moderate expletive

**AMBER**  
= extreme expletive

Once this has been agreed we can produce a lovely, colour coded visual with all the words on (yes, honestly!).

At the top of the list we identify when each of the words are acceptable. For example, we may decide **GREEN** words can be used when frustrated in class. **AMBER** words may be OK if very cross. **RED** words are unlikely to ever be acceptable in a school setting.....unless someone puts some really strong magnets on your earlobe!

We also write a footnote that there is a difference between swearing **AT** someone and general swearing. Swearing **AT** someone is generally not acceptable.

As with any less desirable behaviour we measure progress by monitoring frequency, duration and intensity. The same applies to swearing. We usually initially set an intensity target for a student, i.e. only **GREEN** / **AMBER** words in class.

The key I think, as with anything autism, is to make it visual and try and make it concrete.... but....be prepared to adapt your visual as time goes on.... you never know when someone is approaching you with some magnets!



**Marianne Wooldridge**

Senior Behaviour Consultant, Dimensions

Hi, firstly try not to react. It is hard not to be shocked when your young child swears but this is likely feeding the behaviour and making it increase. It sounds like he knows that these words are 'swear words' so this is not occurring due to lack of understanding.

I would 'model' (demonstrate) and suggest alternative words that he could use in these situations and really exaggerate these at home, make it fun so that he gets a huge reaction for

saying the alternative e.g. "Oh my goodness?!!", "Doh!", "Oh mannnn!". Write down some of the alternatives and prompt him to use these as you see the situation arising.

Share the approach with the school to make sure that everyone is on the same page. Try and encourage them to minimise any reaction to swearing and give a positive reaction for using alternative angry or frustrated words. If things don't improve, you could set up a reward system where he would receive a token/ sticker on a chart for each morning/afternoon/evening without swearing and when he has a certain number he can exchange this for something sufficiently motivating.

*Editor's note: Check out Dan TDM on You Tube, for how to make 'Oh my goodness!' sound utterly cool! Dan is a great positive role model.*



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# SENCo

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**In this issue**

- Jarlath O'Brien on why exclusions of pupils with SEND are on the rise
- Simon Knight outlines a new approach to improving staff's SEND skills
- How to support children with autism during PE lessons
- 4 Lesson Plans

HELPING YOU TO SUPPORT EVERY CHILD

**SENCo**

**PAW PATROL**  
COULD DOPPELGÄNGERS HELP YOUR LEARNERS?

**YOU'RE HIRED!**  
How to recruit staff that SEND lead

**No one is normal!**  
Diversity in SEND

**SEND**  
What's your plan?

**WORK AS A TEAM**  
The truth about autism

WELLBING, ASSESSMENTS + MUCH MORE...

# Welcome to the Alertness Hotel!

Hypo

SENSORY issues are part of autism. Incoming signals can cause overload (when someone is hyper-sensitive), or not provide enough stimulation (when someone is hypo-sensitive). In addition, people don't tend to stay in one state. Depending on the environment, you can be hyper one day and hypo the next. Or, one sense may be hyper and another hypo-sensitive.

This is all extremely difficult to decipher, especially with a non-verbal child, so welcome to the Alertness Hotel, where we can help you take an elevator to your child's optimum state!

Observe your child's behaviour. Do they seem over-alert, bouncing off the walls? Do activities to take them down a few floors in our elevator! Or are they slow to focus? They need to take the lift up from the Basement to the Ground floor! Our Ground floor is

their 'optimum' state of alertness.

With the help of Occupational Therapist Breanne Black, here are the sensory activities that will help us move up and down the floors of the Alertness Hotel. On the left elevator, very alerting activities are on the top floor, lesser ones below. On the right, very calming activities are at the top, lesser ones below.

When the elevator is at rest on the GROUND FLOOR level, those are the activities to keep them there. They are organising activities which help to focus the mind and keep it calm.

This is not an exact science, different children will respond in different ways to each activity, but it will give you an idea of some activities to try at home and at school. AuKids has added its own shopping recommendations to the lists.

*Enjoy your stay!*



## Lift Going Up!

ALERTING ACTIVITIES



## Ground Floor!

ORGANISING ACTIVITIES



## Lift Going Down!

CALMING ACTIVITIES



- Spinning: Using a rotary movement.
- Songs that involve dancing in a circle, like 'Here We Go Round the Mulberry Bush' or 'Ring a Ring o' Roses'.
- Spinning in an office chair.
- Going on a roundabout.

- PHYSICAL: Up and down movement.
- Jogging • Jumping • Cross Trainer
- Bouncing on trampette
- Bouncing on gym ball
- Doing the Hokey Cokey!

- Side to side movements, using songs like 'Row, Row, Row Your Boat'.
- Rocking chair • Rolling over a gym ball
- Song: 'Heads, Shoulders, Knees and Toes.'
- Using a rowing machine.

- Jumping in a circular motion.
- Bouncing on a gym ball in a circular motion.
- 'Log' rolling (hands straight by their sides, and roll! Or, wrap in a blanket and roll, playing caterpillar games!).

- PHYSICAL: Star Jumps • Hopping
- Step ups • Sit-ups • Chair sit-ups • Squats
- Moving from floor to upright position.
- Scooter board activities (buy Scooter Boards at Sensory Direct).

- Wheelbarrow walks • Rocking side to side
- Crawling through tunnel
- Body Sox (get them at Sensory Direct or Ebay)
- Wall pushes • Push ups • Press ups
- Stretching • Standing on tip-toes

- Light touch: Feathers, silk, tickle, extreme temperatures e.g. hot or cold.
- Feely box activities (box filled with materials of different textures).
- Using paint or glue.

- PLAY: Resistive textures: Wet sand, mud, papier-mâché
- Resistive activities, like rolling up newspaper.
- Stretching Theraband or Pilates bands.
- Resistive activities: throwing a bean bag to a target.

- Deep pressure massage • Hand squeezes
- Vibrating toys • Sitting on hands
- Ball squishes (Rolling gym ball slowly over the child who is lying on their tummy).
- Use of weighted items such as a weighted backpack. (Try 'weighted resources' at [www.exploreoursenses.co.uk](http://www.exploreoursenses.co.uk)).
- Use of compression items such as Squeeze Vest/Lycra or tight-fitting clothing. ([www.sensorydirect.com](http://www.sensorydirect.com) sells sensory hug shirts that are relatively inexpensive and look like T-shirts).

- Alerting Smells e.g. Mint. Why not grow your own sensory garden at home or at school?

- FOOD: Using chewy food like fruit chews, dried fruit or chewing gum.

- Chewy /Crunchy food: Crackers, breadsticks, or fruit chews with no added sugar.
- Calming smells: Lavender

- Alerting tastes: Mint, sour, spicy tastes.

- BLOWING: Blowing bubbles through a straw in water.
- Blowing paper balls into a 'goal'.

- Drinking through a straw
- Sucking and blowing activities.

- Alerting sound: fast, loud music. See Jen Gereb in the panel opposite.

- MUSIC: With a regular rhythm - 70 beats per minute is a good speed.

- Slow, quiet music.

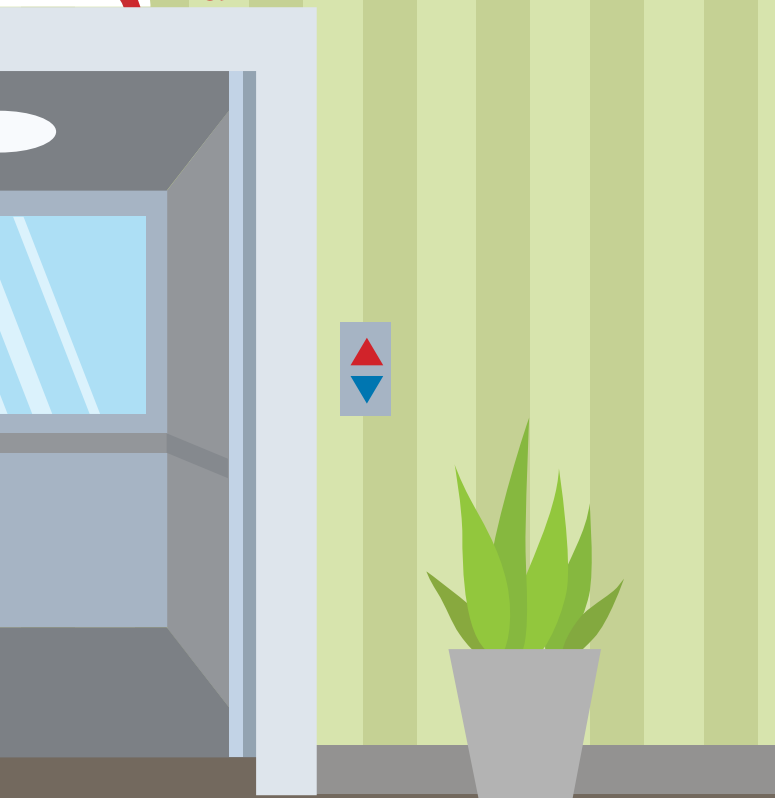
- Alerting visual stimulation: Bright lights, flickering lights, fast moving lights, bright colours.

- ENVIRONMENT: Neutral colours

- Minimal light, subtle light.



Hyper



# the autism show

in association with National Autistic Society

The National Event for Autism

London  
14-15 June 2019  
ExCeL

Birmingham  
21-22 June 2019  
NEC

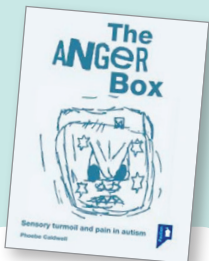
Manchester  
28-29 June 2019  
EventCity

- Hear the UK's leading autism professionals
- Discover 100s of products & services
- Listen to adults on the autism spectrum
- Learn new strategies & approaches
- Access one to one specialist advice
- Interact with sensory features

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## Further Reading



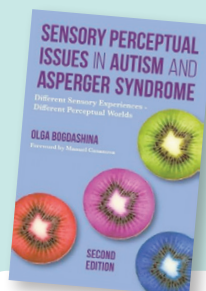
**The Anger Box**  
- Sensory  
Turmoil and  
Pain in Autism

By Phoebe Caldwell



**Making Sense**  
- A Guide to  
Sensory Issues

By Rachel Schneider



**Sensory  
Perceptual  
Issues in Autism  
and Asperger  
Syndrome**

By Olga Bogdashina

## Further Watching



Australian Occupational Therapist Jen Gereb is a top speaker on this subject and she has a range of songs that are recorded at 70 beats per minute on Apple Music, from her albums Say G'Day! Jumpin' Jellybeans and It's Circle Time! Watch her speaking on [www.youtube.com/watch?v=7WIEUxvMOBw](http://www.youtube.com/watch?v=7WIEUxvMOBw) Some of her songs are also available on YouTube.



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Registered charity number 209782

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## 20 pieces of advice from an autistic adult, written for autistic children

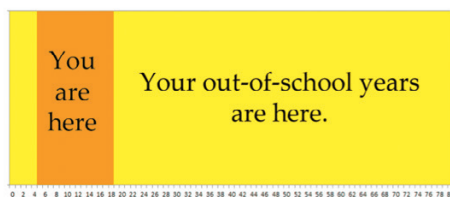
CHRIS Bonnello (aka Captain Quirk) is a special needs tutor with Asperger Syndrome, formerly a primary school teacher. Since 2015, he has become a national and international speaker on autism issues, and the multi-award-winning writer behind [autisticnotweird.com](http://autisticnotweird.com).



My name's Chris and I'm autistic. I didn't know about my autism until I was an adult, because not many people knew about it when I was a child. But now I travel all over the world teaching people about autism. I also help autistic young people who can't go to school, and occasionally I write books, too. I also have a YouTube account. Some of this advice is what helped me when I was your age. Some of it helped my autistic friends, students or godchildren. I hope the advice helps you, too. Everyone is different, so maybe read this with a parent or teacher and decide which bits of my advice suit you best.

- 1** First things first - the world's a better place because you're a part of it.
- 2** Just because you're different to other people doesn't mean you're wrong. The human race *needs* people who are different. The most useful inventions in history were probably invented by autistic or dyslexic people.
- 3** The world is full of beautiful things, and autism helps us to notice many of the beautiful things that other people don't.
- 4** Learn what you're good at and find chances to *do* what you're good at. This is called 'playing to your strengths' and as you grow up it will help you a lot.
- 5** I don't call my challenges 'weaknesses'. I call them 'targets for improvement'. If you struggle with something, it doesn't mean those struggles last forever, and you can still learn how to become better at it.
- 6** You're allowed to make mistakes! In fact, mistakes are a major part of learning. (I have three university degrees and would *never* have achieved them without making mistakes and learning from them).
- 7** Go at your own pace. If you need to slow down to understand something, then slow down.

- 8** If you're struggling at school, don't worry - it doesn't last forever, even if it feels that way. Look at this graph:



■ Years of average lifespan spent at school  
■ Years of average lifespan NOT spent at school

- 9** If you tell an adult something's wrong and they don't listen, tell a *better* adult. And don't just tell them about the problem - tell them the other adult didn't listen to you.
- 10** Sometimes, being the odd one out sucks. Sometimes though, it has its advantages. When I was a child, I'd come up with ideas that nobody else did, and my imagination was incredible.
- 11** It may be difficult, but learn how other people work. How they talk, what hints they use, what they like and what they don't like, what helps them and what doesn't. School intelligence is great, but knowing about *people* is another type of intelligence and it's very helpful.
- 12** I always struggled with knowing what was 'appropriate' and what was 'inappropriate'. It wasn't until I was an adult that I realised that they're different for each person! Right and wrong are usually the same, but what's 'appropriate' changes depending on who you're talking to.

- 13** If someone demands eye contact, stare at their nose.
- 14** When you're angry or upset, take a few extra seconds to think before doing something you regret. Most big mistakes happen because someone does something without thinking first, and you'd be amazed

how much just a couple of seconds can help you.

- 15** Play chess! Especially if you struggle with that last point. It helps you to think your actions through, teaches you how to predict other people's actions, and it's great fun when you outsmart someone!
- 16** Have your own safe spaces for when you're feeling exhausted, upset, angry or if you just need time to yourself for a bit. Stay in those spaces for as long as you need, and come out again once you're better.
- 17** Everybody feels anxious. Some people are just better at hiding it.
- 18** Being brave doesn't mean not being afraid of anything - it means being afraid but facing your fears anyway. So if you feel nervous about something, do it anyway. It'll make you braver.
- 19** When you're happy, make a list of things you love about life. Read it when you're sad.
- 20** And finally, one last bit of encouragement. When I started school, I had the language skills of a two-year-old. Now I speak in front of big crowds for a living. If you struggle with something as a child, it doesn't mean you'll never do it. Practice helps, determination helps, and bravery helps.

I wish all of you the very best as you grow up, and I hope some of this advice has helped you.

### Further Information

Love this article? We nicked it (with Chris's permission) from a much longer version which you can find in full at [autisticnotweird.com/advice-for-children](http://autisticnotweird.com/advice-for-children)

Follow Chris on You Tube at [www.youtube.com/c/AutisticNotWeird](http://www.youtube.com/c/AutisticNotWeird) and Facebook at [www.facebook.com/autisticnotweird](http://www.facebook.com/autisticnotweird)

# 10 Tips on Tackling Change

On social media forums, we notice a lot of parents asking for help in moving their children onto something new. The questions come in many guises, but they all boil down to one thing – tackling change.

This is hardly surprising. Rigid thinking is a key player in autism. Comfort lies in the familiar and change feels very threatening. That doesn't mean to say that you can't bring change about, though. You just need some different techniques!



## 1 Time It Well

Try and tackle one change at a time and choose a time when everything else in the child's life is reasonably predictable. You won't be able to work on this if you're having a really hectic time of it (and you may feel that you're *always* having a hectic time of it, but it's all relative!)

## 4 Get Used to Its Presence First

If the change involves something new (like a uniform), first get your child used to its presence visually without any pressure to use it at all. Some years ago, our volunteer Tim desperately needed a new phone, but the change was very difficult (his old one had long stopped being manufactured). We gave Tim a new phone in a cover that reflected his special interest and told him to keep it in his pocket for a few weeks. By the time it came round to using it, it felt like a bit of a friend.

## 2 Understand Why Change Is so Difficult

In autism, change is linked to anxiety. Your child's rigidity isn't caused by being stubborn, it's caused by neurological differences leading to fear of uncertainty and of the unknown. As author David Carbonell says about worriers: 'You experience doubt and treat it like danger'. So, the very thought of change puts autistic children into 'fight or flight' mode. It can be an over-reaction, but it feels very real to them. This is why change needs to be gradual, so it doesn't feel like a shock or a threat.

## 3 Make It Gradual

Step by step change is still change. As the saying goes 'It doesn't matter how slowly you go, as long as you don't stop'. Make 'move towards' targets, rather than 'completed' ones. Take it from us, you'll look back in ten years and you really won't remember how long these milestones took your child to reach.

## 6 Pair It With a Special Interest

It's not just that special interests are motivating; they're calming, too. Focusing on something you like helps to keep those stress hormones at bay, and makes thinking more flexible. Try and incorporate the special interest into the change itself. Get their favourite characters to encourage them!

## 5 Link Change to Reward, Rather Than Punishment

Hopefully, having read Point 1, you'll recognise that even making small changes is a real achievement for an autistic child. So, rather than taking away a biscuit if they don't drink from their 'big cup', give them two if they do! Praise every small attempt at change – it really is a big deal.

But please note, some autistic kids get overwhelmed by a huge positive fuss... so agree a praise signal that works for them!

## 8 Stay Calm

It's frustrating when you're in a hurry for your child to grow up, particularly if their siblings leapt through certain stages without any difficulties. But the experience of pressure from others is something else that's linked to anxiety with autism – and autistic kids absorb your feelings like a sponge. So, try not to get too emotional about setbacks and remind yourself that you're tackling this at a different pace, and that's okay. You'll get there.

## 7 Be Aware of Sensory Issues

If your child doesn't like public toilets, it may not be the toilet that's the problem, but the noise of the hand dryer. Change in this respect is going to be difficult to achieve without a set of headphones and a towel, plus lots of 'no noise' reassurance. Debby's son Alec has learnt to tolerate hand dryers because he found one that lit up blue, which he loved. This helped him to over-ride his anxiety.

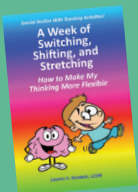
## 9 Get Others on Board

If you're using reward systems, communicate them to others so that your approach is consistent whatever the environment. Use your friends and family to support you.

## 10 Give Reasons Why

"But you're a big boy now!" "Only babies do that!" and "Don't you want to be a grown up?" These phrases may work on other kids, but they often fail to convince autistic kids that the stress of change is worth it. Seriously, they don't care if it's babyish or not, they just want comfort. You're going to have to do a better sales pitch, telling them WHY this change is important, but without making them afraid. So instead of saying: "Because when you go to big school you won't be able to use that cup!", try: "Because when you go to big school, you'll be using this type of cup and you'll feel great if you're used to it already!" Help them picture themselves feeling successful, rather than fearful.

### More reading on change



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

By Lauren H. Kerstein

#### From the AuKids archive

- Ask the Experts: "My family are hostage to my son's rigid routines. Do we adapt our lives to suit him or are there techniques we can use to influence his rigid behaviour without causing a meltdown?" *Issue 10*
- Ask the Experts: On having to get things 100% right. *Issue 22*
- Ask the Experts: On resistance to demands *Issue 28*
- Ten Exercises for Stretching the Comfort Zone *Issue 28*
- From a Black and White World to Thinking in Colour: How to improve flexibility of thought with author Lauren Kerstein *Issue 33*



# The Smart Approach to Interventions

As a parent, it's very hard to weigh up various autism interventions without having the right kind of scientific knowledge. This – and the love we have for our children – can make us vulnerable to following dubious interventions. Fortunately for us, in 2015 a helpful guide called *Choosing Autism Interventions* was published by Research Autism in partnership with Dimensions and Autism West Midlands.

The guide takes you through all the autism interventions currently practised, weighing up the evidence to suggest their success or otherwise and evaluating any risks associated with them.

At the back of the book is some golden guidance on weighing up whether or not to choose an intervention. With the permission of the book's authors, we've reproduced some of it here. Ask these questions and you'll approach an intervention with the right information.



## Key questions to consider when choosing an intervention

### Background

- Find out the full name of the intervention or programme and whether it has any other names.
- How was the intervention developed? (For example is it based on clinical or personal experience, religious or philosophical belief, does it come from another field of medicine or disability?)
- Were people on the autism spectrum actively involved in, or consulted on, its development?

### Evidence

- Consider the evidence in favour of this intervention. (Including research studies, personal accounts from other people.)

### Philosophy & aims

- Consider the aim of the intervention or programme.
- Think about the underlying idea or philosophy behind the intervention or programme.
- It's important to know if it focuses on one specific skill or problem or whether it's a general approach.
- Ask yourself if you're happy with the philosophy and aims of the intervention or programme.

### Key features

- What type of intervention is it? (Is it a training programme, a special diet, a medication or a service?)
- Look at the major features of the intervention or programme.  
For example:
  - Who delivers the intervention
  - Where it's delivered
  - How the intervention is delivered
- Is the intervention or programme adapted to the needs of people on the autism spectrum? If so, how?
- Is the intervention or programme personalised to the needs of the individual? If so, how?
- How is it different to any similar interventions or programmes?
- You'll need to ask if you have to undertake or stop other treatments or activities if you start this.

### Costs

- If payment is involved, you could ask how you get help to pay for the intervention.
- Check how much in total the intervention costs (including enrolment fee, training, materials or equipment (including renewals), fees, administration charges, travel costs, follow up or recurring costs such as re-registration, other additional costs).
- Find out whether you can get your money back if the intervention or programme is not effective.

### Participants

- Which group of people is this intervention or programme supposed to help? (Anyone, people on the autism spectrum, children?)
- Are there any people who should not undertake this intervention or programme – such as people with epilepsy or other medical conditions?

### Equipment & materials

- Find out about any materials you'll need and any special adaptations or modifications you need to make to your home.

### Training

- If you need any training in order to undertake this intervention or programme, look into any costs involved and the length of time it will take, as well as who provides the training and what it involves.

### Evaluation

- Read what people say about the intervention (including the providers, people on the spectrum, parents, independent professionals, research evidence).
- Take into account whether programme staff are open to suggestions about improvements from people on the autism spectrum, families and other professionals.
- Ask if you can talk to other people (such as individuals on the autism spectrum, parents) who have been involved with the intervention.

## Time

- You'll need to know how long the intervention or programme lasts and how often it takes place.

## Staffing

- What is the background of the programme director and staff?
- Which staff will be working with me or my child and can I meet them before making my decision?
- What experience do these staff have of working with people like me or my child?
- Do programme staff co-ordinate their work for me or my child with other professionals?

## Regulation and complaints

- Is this intervention or programme regulated by an external organisation, such as a professional association or university? If so, when was the date of the last audit and what did it say?
- Is there a complaints process? Have there been any complaints or legal disputes about the intervention or programme? What were the outcomes of those complaints or disputes?

## Supply & availability

- Find out the organisations and individuals providing this intervention or programme. If there is more than one supplier, what is the difference between the suppliers?
- Is there a waiting list? If so, how long is it and do I have to make a payment to be put on it?



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## Red flags: signs that an intervention or programme may not be what it seems

### Celebrity endorsement

(Why should celebrities know more than you?)

### Commercialisation

of the intervention or programme (expensive fees or opportunities for you to make money by becoming a re-seller of the intervention).

**Claims** that the intervention is easy to use, requiring little training or expertise.

**Use of outdated** or incomplete research studies and reviews which don't show the full picture.

**Claims** that the intervention is effective for many conditions, disorders and diseases.

**Claims** of high success rates and rapid results.

**Claims** that other proven interventions are unnecessary, inferior or harmful.

### Glitzy presentations

(for example videos and PowerPoint presentation) which include bogus scientific data.

### 'Research' findings

that have not been published in reputable peer-reviewed journals.

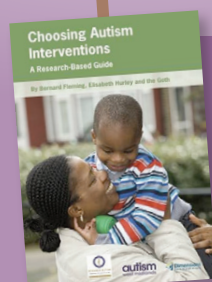
**Warnings and reprimands** from reputable organisations, such as the National Institute for Health and Care Excellence or the Advertising Standards Authority.

**Use of words** like 'miracle', 'faith', 'trust', 'cure', 'recovery'.

**Hard-sell techniques** (including emotional blackmail or special offers).

**Remember:** if an intervention looks too good to be true then it probably is!

**N.B.** These questions and flags are adapted from materials originally developed by Richard Mills, who was indebted to Dr Judith Gould, Professor Gary Mesibov, Professor Patricia Howlin, Damian Milton, Bernard Fleming and the late Dr Lorna Wing and the late Professor Eric Schopler.



To read more great advice - including how to evaluate research studies - and to look up the current evidence on specific interventions, buy *Choosing Autism Interventions, A Research-Based Guide* (published 2015) by Bernard Fleming, Elisabeth Hurley and The Goth. Published by Pavilion. The Research Autism information team is now part of the National Autistic Society.

# It's Okay to Be Me!

Helping Our Super-Heroes to Champion Themselves



**AUTHOR** Rachel Jackson uses her experiences with her two young sons in two stories for children – *'The Thing – A young Boy's Journey with Asperger Syndrome'* and *'My Brother has a Thing...and I Want One'*. She also runs Changing Dialogues – supporting organisations, teams and individuals with leadership, emotional intelligence and resilience development.

We were at my sister-in-law's wedding a few months ago. Weddings are like chaos in uncomfortable shoes for most of us. For my son Ben, who has autism, they are a cacophony of expensive perfume, a tidal wave of emotions, a gluttony of food and a rush of exuberant dancing and singing. Unlike many of his peers, he loves them!

It hasn't always been this way. I recall one wedding during which I ended up stomping my way around the headland in Cornwall, with a screaming toddler who had been intent on rendering my best friend's speeches inaudible.

Ben struggles with sensory overload. He is a barometer for emotion and he doesn't always manage to regulate his responses to these things.

At seven, he is just starting to notice that people don't seem to want to play with him. His brother has a birthday party to attend every other weekend and he has none. He has always found groups hard to navigate - and I sympathise - I sometimes do, too!

Back to the wedding, where I found him sitting calmly outside in a courtyard. He told me in his very adult voice that he'd felt a little overwhelmed and decided to take a break - the music was too loud.

Filled with pride at this active attempt at regulating his senses, I suggested we use his ear defenders for a bit.

He grimaced. "People will laugh at me and think I'm weird," he stated.

This is a first for us - the first real sense of shame or embarrassment at his condition.

I have to admit that lately I've noticed him far quicker to flare up at me when I tell him off in public. His sense of self is clearly beginning to form, but I've never known him to be ashamed of his autism or sensory needs and I wasn't quite sure how to respond. So we sat for a

while talking about it and came up with some options.

He didn't want ear plugs in as they hurt. He didn't want to go home as he wanted to dance. But equally, he didn't want people to think he was odd.

We eventually came up with a plan and jointly approached the DJ, informing him that Ben had sensitive ears and wondering if he could turn the music down a little as he loved to dance. Duly engaged, my son and the DJ negotiated an appropriate balance using hand signals and thumbs up...and the dance moves began.



Since my son's diagnosis three years ago, I've tried to recognise moments when the world is not naturally set up for autism and to encourage my son, just like any young man - to let others know what could change to make it more so.

He will now ask for what he needs in a restaurant. He will find an assistant at the supermarket and ask where something is. He will ask for doors to be opened or closed

**"He learns from me that it is OK to be imperfect, safe to be broken and totally normal to be changeable...but he also learns how those feelings can be managed and overcome."**

to suit his needs. These are simple things. But they teach him that he has a place in this world. They help him to realise his own ability to adjust his environment and they combat those times when he feels the odds are stacked against him.

We spend so much time dealing with the physical needs of our kids and tackling their 'symptoms' that some of the more basic psychological needs we would nurture naturally in our neurotypical kids can get neglected.

As a Corporate Consultant specialising in Resilience and Emotional Intelligence, I am frequently standing in front of adults speaking about negative self-talk and the importance of balanced attribution styles (the process by which individuals explain the causes of behaviour and events to themselves). Yet it took me a long time to apply those same principles to my son.

Whilst traditional perspectives on autism suggest a lack of or reduction in empathy, I believe those on the spectrum to be 'hyper-empathetic'. My son's issues stem from attempting to interpret the rich stream of emotional signals he receives and to respond appropriately.

This hypersensitivity can have a huge impact on his self esteem. Whilst remarkably immune to sarcasm, he is extraordinarily sensitive



to teasing or criticism, hugely concerned about how others are feeling and intensely aware when others around him are tense.

Sadly, he often takes more responsibility for this tension than he should - and the resulting anxiety and fear of failure becomes an additional barrier to taking the right choice of action.

We are lucky - my son seems pretty resilient at the moment. He is still prepared to try new things; he will still approach people and ask to play; he still speaks of himself in positive terms. Others are not so lucky. I have a friend whose ten year-old is already talking about self-harming and wishing he hadn't been born. In fact, estimates of self-injurious behaviour (SIB) and low self-esteem in autism vary but most suggest that autistic children demonstrate SIB far more than the rest of the population. Reports of low self esteem and rates of depression in autistic people are also far higher than average.



**SNAPPY SUITS:  
RACHEL'S SONS BEN AND LEO  
DRESSED UP FOR THE WEDDING.**

Part of the problem comes within the spectrum itself. Autism comes with difficulties in identifying and reflecting on internal emotions. Autistic children find it harder to say how they feel, as they lack both the words and the recognition of those internal emotions. Usually, children learn about emotions by watching other people. Children on the spectrum find it harder to interpret others' emotions and so the usual connections aren't made and expressing them becomes harder.

So what can we as parents and professionals do to help?

Perhaps the simplest opportunity to build self-esteem comes in offering greater choices to our children.

Lately, I've tried to stop myself taking the easier route of making choices for Ben. I give him the option: "Would you like shorts to go out in the hot sun - or your tracksuit trousers?" Yes, he will probably be hot. Does that mean I get to take away his right to choose (and find out for himself)?

I also spend time with my son helping him to understand the currents of emotion around him. I don't hide my own emotions from him - he has seen me crying, angry, depressed, distraught, confused and stressed - and each time I explain to him where that emotion comes from, what it feels like and how I handle it.

He learns from me that it is OK to be imperfect, safe to be broken and totally normal to be changeable...but he also learns how those feelings can be managed and overcome.

Like the rest of us, our children are learning to live in a world filled with perfectionism and criticism - and much of it they will take to heart. I try to balance that with praise and interest in my son's achievements and with reassurance that it doesn't always need to be right - it can be different...and fun. I tell others about his autism without embarrassment and I help him to find words to express it for himself...which brings me to a new place I want to share...

Last week my son was approached by two boys he knows, who spoke to him about his school - since he clearly doesn't go to the local school. He told them he now went to a school in Cambridge...and I waited for him to say it was a school for children with autism. He did not... and I wondered...At what point does his diagnosis cease to be my secret to tell, my story to share - my right to tell others about? At what point do I step back and allow him to choose whether he tells others about it or not? He is seven...Is it ever too early for him to choose his own way?

Our children learn from us what they should be ashamed of. They pick up from us what they should judge or disapprove of, notice or comment upon. They develop their sense of who they are from listening to how we talk about them and ourselves.

Our children deserve to feel proud of themselves, secure in who they are and able to make their own choices about how they present themselves to the world.

They deserve their own story.

**You can find out more and buy Rachel's books for £8.50 each at [www.facebook.com/TheAspergerThing](http://www.facebook.com/TheAspergerThing) or at [www.senbooks.co.uk](http://www.senbooks.co.uk)**

**Rachel Jackson has written two very important books to help children come to terms with their feelings about autism.**

## The Thing

I'm keenly aware that the preferred way of describing autism (including our own at AuKids) is that it's a part of your personality and for this reason, referring to it as The Thing may strike a few alarm bells. But actually, it's a very clever method of personifying a part of you that may be a friend in some respects but a bewildering annoyance in others. Think of The Thing as more like an avatar and you'll be closer to what the author had intended.

With wonderful illustrations by Zeke Clough, The Thing doesn't try to describe autism, but instead what it feels like to have a condition which sometimes makes you react in ways that other people find alarming. In a sense, this gets autism across very accurately from a child's perspective. They don't care what it's called, they only care that they have 'a thing' that sometimes makes them do things they don't understand. In a wonderful analogy, the boy in this story grows, but The Thing does not - he learns enough about his condition to stop letting it rule him.

Rachel's added some great tips at the end of the story for both parents and teachers about using this book to its best advantage.

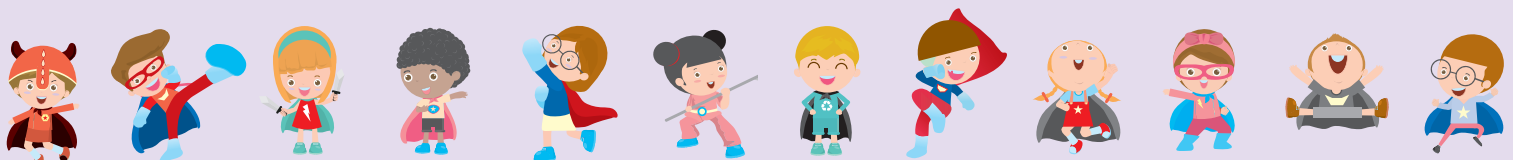


## My Brother has a Thing - and I Want One!

What I like

about this book is that it isn't a lesson in understanding autism. It purely reflects how it feels to live with a brother or a sister who has a condition that can make them a difficult housemate! In doing so with warmth, charm but above all honesty, it will help children to own and accept their feelings and not to feel bad or guilty about having those difficult emotions. It will also help them to share their thoughts honestly with their parents. In rhyming couplets reminiscent of Julia Donaldson, it's a positive boost to any sibling's bookshelf.

Reviews by co-editor Debby Elley.





# The Last Word

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

## THE GUILT MONSTER

Despite writing about autism for the last 10 years and knowing a thing or two about the subject, I still suffer from that permanent headache brought about by the Guilt Monster.

The Guilt Monster plagues good parents by telling them that they aren't doing enough. If your conscience should always be your guide (according to the Pinocchio song) then your Guilt Monster is the part of you without a map or compass but with lots of confident ideas about the cleverest route to take.

Usually I feel as if I'm spending enough quality time with my kids, but like all parents I have times when I hit a plateau and I'm not particularly motivated to work on their next milestone. It will be at about this point when I hear or read something written by a parent who is very much motivated to work on the next milestone. I mean, for all I know these people hit plateaux just like I do, but at this particular moment, they are making amazing strides with their autistic kid. This prompts Guilt Monster to rise up and roar: "WHHHHHY AREN'T YOU TRYING THIS?"

If I had tried harder, would Alec talk? If I had tried harder, would Bobby have lots of different interests?

Fortunately, I have a very balanced husband who reminds me that we have our lives, too. Guilt Monster is terribly counter-productive because it will probably persuade me to write some knee-jerk email, or bowl everyone else over like skittles as I storm towards someone who will help me NOW. Guilt Monster doesn't lead to reasoned, rational decision-making.

Chatting with Tori, I was reminded that parents of neurotypical kids have Guilt Monsters, too. It's actually part of parenting. It shows you care.

I've decided that in order to keep Guilt Monster at bay, the only thing I really need is a very sturdy compass. What am I aiming for? My kids to be settled, happy and in a state where they can relate to others. As long as you know where you're going, the Guilt Monster won't push you off track with its 'big ideas'. Get inspired by all means. Get ideas - and use them. But don't feel guilty. We can't work at anyone else's pace but our own.



Don't miss our next issue - out end of April!



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