



Issue 29
Autumn 2015

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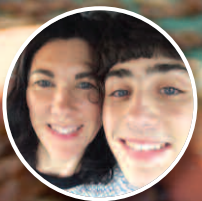
Positive Parenting for Children with Autism Spectrum Conditions



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Autism across the
Atlantic



Just Can't Get Enough
Why spectrumite kids get
stuck in a loop



**Wanna Be
Startin' Somethin'**
The parents making
a difference



PLUS

Olga's blog, autism-
friendly gift ideas and
TONNES of toy prizes!



Letter from the Editors

Debby Tori



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Hello and welcome to
Issue 29!

First off a lovely announcement...Our co-editor Tori is expecting a baby boy! He is due on November 9th. Debby, Jo and Tim wish Tori all the best with her new bundle of joy.

Meanwhile, inside this issue you'll notice a cartoon on our readers' page. Our new character is Simon, and in our **Simon Says...** illustration, he'll be playing social detective trying to spot clues for the best thing to do next. Simon Says...is a puzzle for you and your child to work on together. Let us know what you think of it.

For those who aren't quite at Simon's level of understanding, we have our new **Wow! - Do It Now!** corner, where autism expert Gina Davies suggests irresistible activities to promote joint attention, communication and fun together. Thanks Gina! You can see Gina's work at www.ginadavies.co.uk and follow her Facebook page for more fun things to do.

It was Eleanor Roosevelt who said *'The future belongs to those who believe in the beauty of their dreams'*. A handful of just such people appear in our Mission Improbable feature, where we've spoken to parents of children with autism who felt passionate about making a change for the good of everyone else. Not only does it make inspiring reading, it should also give you a number of new products and services to investigate!

There's a lot of people in this country looking over their shoulders right now, to see if anyone else is doing it better. By 'it' we mean autism intervention... We hear so much about autism in America that we felt it time to talk to the people who were actually living there. Find out about the state of the States on Pages 8-9.

Having stepped across the pond, it's closer to home for your festive shopping round-up. Don't forget the AuKids clothing range on that Christmas list, with positive slogans for family and friends, both those with autism and without. www.finsdesignandprint.co.uk

Do you have a daughter with autism? We are preparing a feature on girls on the spectrum and would love to hear from you! What do you think people misunderstand most about girls on the spectrum? Send your answers to editors@aukids.co.uk and we may draw from your wisdom in our January issue.

In our next issue, we'll also be publishing our annual round-up of autism conferences and exhibitions. If you have any you'd like to tell us about, send them to us no later than November 30th to editors@aukids.co.uk

Have a great holiday and we'll see you in the New Year!

Tori & Debby

e-mail: editors@aukids.co.uk

COMPETITION WINNERS FROM ISSUE 28:

- **Dentist Book:** Amanda Ayres, Cheshire; Jo-Anna Dem, Reading; Gary Robertson, Chippenham; Susan Batley, Kings Heath; Alison Holmes, Ilminster.
- **Poisson Rouge Subscriptions:** Nicola Naylor, Warwickshire; Paula Greco, Uruguay; Caroline Read, St. Helens



PARENTS
£35
PROFESSIONALS
£100

autism a hands on approach CONFERENCE

Date: 24th November 2015.

Venue: Stepping Hill Hospital, Stockport.

Speakers Include:

- **Phil Christie** talking about emotional Wellbeing
- **Lynne Moxon** on Sex and Sexuality
- **Chris Oliver** on behaviour disorders in children and adults with ASD;
- **Jonathan Green** reports results of early intervention studies
- **Sarah Parsons** on Using I.T. for people with ASD
- **Corinna Laurie** on the 'Sensory Diet'.

Further Details:

Contact Tanya Farley on 07966 399 709.

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

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

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PHOTOGRAPHY:
Front and back
photography by *David Laslett*
DIGITAL PHOTOGRAPHY
David Laslett: www.manchesterphoto.com

PRINTING:
R and P Printers, Dukinfield

GRAPHIC DESIGN:
 periscopestudios
www.periscopestudios.co.uk

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



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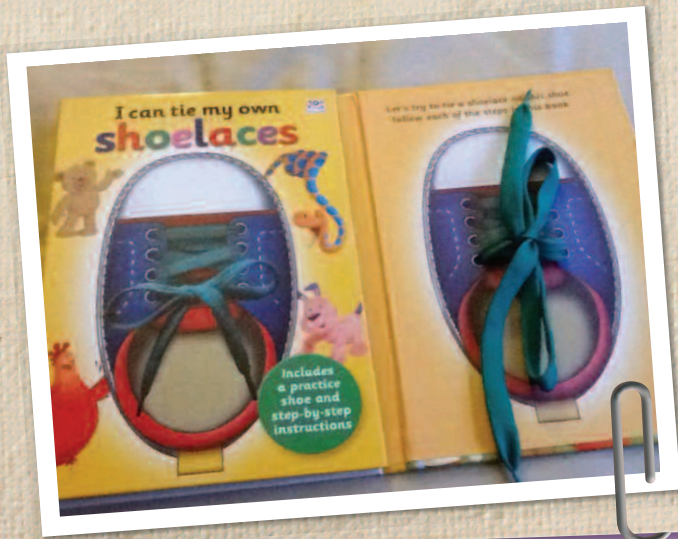
READERS' PAGE

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

Dear AuKids,

I would like to recommend a book for anyone attempting the dreaded shoelaces with their child. My daughter, just 11, has finally cracked it tonight, after previous attempts. I bought the book, which was really cheap from Home Bargains, but it's also available in Morrison's and Costco. She wasn't keen at first and there were tears at the thought of it (plus I think she thought the book was a bit young for her) but within three or four attempts she cracked it. ALL VERY PROUD in our house tonight!

Michelle Hayes



Wow - Do It Now!

Ideas for little sensory seekers with autism expert Gina Davies www.ginadavies.co.uk

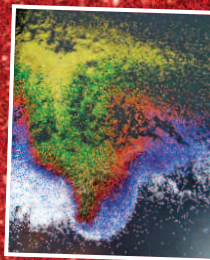


1 Find some small attractive pots.

Buy similar at www.traidcraftshop.co.uk



2 Fill with glitter and place the pots on a dark tray or background.



3 Open each pot in turn and pour out the glitter in a stream, then tilt the tray or paper and watch the glitter merge...

...and a very sparkly Christmas to everyone!

CHEWING IT OVER AFTER ESCAPING THE DRAGON'S DEN

Our friends Jenny McLaughlan and Lorraine Young from Chewigem (www.chewigem.co.uk) have appeared on Dragon's Den but left disappointed having pitched for a £30,000 investment for 15% in their business. The business has three brands: Gumigem, (silicone mummy necklaces), Chewigem - a range of discreet silicone jewellery for the sensory market (our kids!) and Moozels, a new range of innovative kids' clothes. The show aired on Sunday 30th August at 8pm.

Here's what Jenny told us:

'It was going well with two potential investors still in and Deborah Meaden, the last dragon to decide, looked like a potential investor - until the numbers were unpicked and a flaw was found. I knew something was wrong, but under the pressure of the Den, my mind went blank. I was gutted and furious with myself. But despite that, I was thrilled with how our products were received.

'On the long drive back from Manchester, my brain kicked in and I realised what I had done... I had forgotten to take out the closing stock. This would have answered their questions and improved our profit figures. The nerves just get to you.

'Despite the disappointment, we got some really good advice off the 'dragons' and I have now got a mentor. So although it's tough to have missed out, it has moved us forward and we will continue to grow and improve.'

WIN
an Emotichew
from Chewigem
- Page 4.

Christmas Puzzler

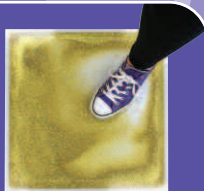
Simon Says...

Simon is a little boy who has autism. Sometimes he has to think quite hard about what to say or do next. Use our Simon cartoons as talking points with your autistic child.



'Little white lies' can be popular at Christmas. Why is that? Chat about the picture. What will Simon say?

Add Sparkle to the Season With This **GLITTERING DISCOUNT!**



When AuKids exhibited at the Autism Show, we were drawn like magpies to the colourful Mike Ayres Design stand. Their Glitter Liquid Floor Tile had us mesmerised, drawing delighted smiles from Tori and spoilt 'wantit-wantit-wantit' nags from Debby. This provides a wonderful visual and tactile experience. The golden glitter inside swirls and sparkles around you as you move about on the tile. It will withstand any amount of jumping and strenuous use by children and adults as well as the weight of a wheelchair.

The Liquid Floor Tile can also be used on a table top or any flat surface and manipulated with your hands. A small amount of pressure creates a dramatic effect.

Mike Ayres Design's usual price is £78 per tile (incl. VAT), but after seeing our pleading little faces, they've offered AuKids readers a whopping 35% discount! So to buy it for £50 incl. VAT plus £4.80 p&p, just go to www.mikeayresdesign.co.uk, visit their webshop and use the discount code:

Aukidsxmas

Happy Christmas from
Mike Ayres Design and AuKids!

Glitter Liquid Floor Tile product code: 1348-51
Size: 50 x 50 x 0.7cm

Reviews & Prizes



BOOK
Choosing Autism Interventions: A Research-Based Guide

By Bernard Fleming, Elisabeth Hurley and the Goth
Published by Pavilion Publishing
£19.95
ISBN 9781910366769

A book like this is long overdue in the autism community. We welcome it with open arms and a standing ovation. It's a smart, well organised guide to most of the autism interventions available and a brilliant antidote to those making outrageous claims that aren't based on scientific evidence. Most of us don't have a background in scientific research and not only that but we don't have enough scientific knowledge to accurately assess the quality of research evidence, either. When something is 'proven to be effective', is it good research that's proven it? Erm, pass...

This handy reference does the work for you. It's a joint initiative between Research Autism, Autism West Midlands and Dimensions – all organisations for which we have the greatest respect. The authors are known to us, in fact you may remember Liz Hurley (not *that* one!) from the article we wrote on the science behind autism in Issue 21. Bernard Fleming is the Information Manager for Research Autism, the only autism organisation currently accredited to the NHS Information Standard. The person mysteriously named 'The Goth' is James Mason, editor of Asperger's United, a publication written by people on the spectrum, for people on the spectrum and published quarterly by the NAS.

Research evidence for each intervention has been weighed up and the overall therapy is summarised for benefits and risks. If you want the bottom line without a lot of blurb, this is it. In conjunction with that, it has some notes on why evidence may be difficult to assess, for instance in the case of those where individual

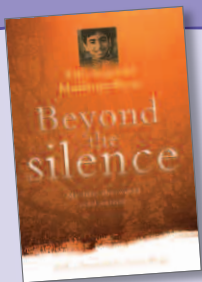
practice varies greatly. This also bluntly states where insufficient evidence is available.

Many people, especially advocates of some therapies who have witnessed great improvement in individuals, may find it hard to accept that scientific evidence isn't sound enough to wholly embrace a particular intervention. This doesn't mean to say that there aren't significant benefits to using some of these interventions, but it's hard in some cases to quantify the beneficial results over time, in fact scientifically speaking it may be nearly impossible. What this will say is whether the intervention carries any risk, so whether it's proven or not scientifically, this is helpful.

The green section at the back of the book, including key factors to consider when choosing an intervention, is also invaluable. Not only does this book do the hard work for you, it skills you up so that you won't fall for any outlandish claims in future. Of these, the list of 'red flags' to watch out for were my favourite. Signs that a therapy programme may not be what it claims include celebrity endorsement and use of words like 'miracle'. Persuasive perhaps, but scientific – hardly.

Bravo, editors.

Debby Elley,
AuKids co-editor



BOOK
Beyond the Silence: My Life, the World and Autism

By Tito Rajarshi Mukhopadhyay
Published by National Autistic Society
£7.99
ISBN 9781899280315

Tito is a remarkable young man with severe autism and this is the first of his many books. Although he remains almost completely non-verbal, through the persistence of his mother and a small army of professionals, Tito has learned to communicate through a language board and writing with a pencil.

Most of the book comprises Tito telling his own life story in two sections, written when he was eight and 11 years old, along with a short philosophical story - The Mind Tree (written from the perspective of a tree who is gifted a mind) - and a collection of poetry.

For those who have ever wondered about what is going on inside the mind of someone with no verbal communication, this book will prove endlessly fascinating. Tito's incredibly sophisticated use of language combined with his depth of understanding and wisdom mean you will find it very hard to believe that this was written by a young child (though the late Lorna Wing testifies to its validity in the foreword).

This short book is an extraordinary and moving collection of writings that will no doubt make an impression on any reader, but it will be especially of interest to those who know someone on the more severe end of the spectrum.

Mark Haworth,
AuKids Readers' Panel

WIN A COPY!
We have **THREE** copies of **Choosing Autism Interventions** to give away to AuKids readers.

Q: Who is The Goth?

Send your answer to us at competitions@aukids.co.uk no later than November 30th 2015 with 'Goth' in the subject header, or send a postcard to us at AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE. As usual, three correct winners will be selected at random after the closing date.

Good luck!

COMPETITION TIME!

Well by now you will have checked out Chewigem's account of their time spent in the Dragon's Den on our Readers' page. To celebrate the company's well-deserved small screen appearance, we're giving away three children's EMOTICHEWS, each worth £7.95. Emotichew is Chewigem's chewable non-toxic bangle that doubles as a communication aid and message to others. Simply show the side that represents how the person is feeling. The red side says 'Leave Me Be' with a little angry Chewigem face and the green side says 'Talk to Me' with a happy little Chewigem face. It's a subtle indication of when space is needed, and could also be

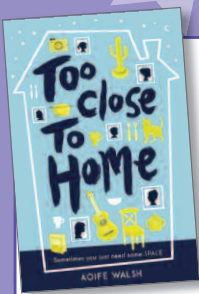
used to indicate when help is required in the classroom.

To enter the competition, simply answer this question: **Which dragon was the last to be 'out' when Chewigem presented their products on Dragon's Den recently? Was it: a) Deborah Meaden, b) Peter Jones, c) Sarah Willingham, or d) Touker Suleyman?**

Send your answer to us at competitions@aukids.co.uk with 'Chewigem' in the subject header, no later than November 30th.

GOOD LUCK!





BOOK Too Close to Home

By Aoife Walsh
Published by
Andersen Press
£7.99
ISBN 9781783443000

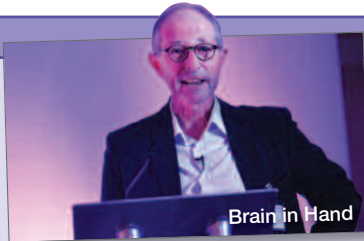
This novel's written by a mum of three. Two of her boys, aged 12 and 4, have autism. Although it's primarily aimed at teenagers, *Too Close To Home* is also an enjoyable and relevant read for adults. The story focuses on Minny, a teenager from a complex family. Since her father left home, Minny bears the brunt of responsibility within her family. Her mum relies on her to help support her older sister Aisling, who has autism, her younger sister Selena and her baby brother, Raymond. The family live with their eccentric grandmother, adding more weight onto Minny's already overburdened shoulders.

The book starts off slowly, but I quickly became used to the amount of dialogue and the conversational style used. I soon started to empathise with Minny and the challenges she faced as a teenager trying to find her place in the world, whilst also trying to endure her chaotic lifestyle.

Her father's return with a girlfriend and new baby on the way poses even more difficulties. Although the book focuses on Minny's troubles, it does give an insight into the responsibilities and pressure of having a sibling with autism.

The story is moving, warm, funny and an enjoyable and interesting read. It would be useful for anyone who has a connection with autism and wants to gain more of an understanding of what it's like to live with someone on the spectrum.

Melodie Blake,
AuKids Readers' Panel



CONFERENCE Autech Old Trafford Manchester October 1st 2015

It's ambitious to host a UK event on autism and technology and downright brave to dedicate your first national conference to it. The charity behind Autech, Wirral Autistic Society (renamed Autism Together on the day itself), weren't shy of a challenge, though. That said, there's some distance to go before this idea reaches its full potential.

An early highlight was David Fry, chief executive of Brain in Hand. He introduced the company's innovative app of the same name, whose developers had spotted an opportunity in 2009 to use mobile technology to give autistic people instant coping strategies. Brain in Hand means that personalised strategies can be uploaded onto software, categorised and accessed in a moment of potential anxiety. This, says David, compensates for impairments in executive functioning, reduces anxiety and promotes independence. It's been dubbed a 'back up mental filing cabinet' and has a mood monitor linking to the person's own support network.

The Autism in Practice team reported on their experiences using the communication app Proloquo2go. This is only one tool; in future I'd like to hear from experts who have tried a range of systems so that they can compare their benefits and drawbacks. My late arrival (I'm the kind of

mum who treats conferences as some sort of enforced respite) meant that I missed Dr Matthew Goodwin on the use of biometric readers to help unravel anxiety triggers. I also missed Kaspar, a humanoid robot that helps teachers support children with autism. He was introduced by Dr Ben Robins from the University of Hertfordshire.

I was delighted, however, to catch 17 year-old Rosie King, formerly the young presenter of the award-winning Newsround Special 'My Autism and Me' and a future regular on the conference circuit, I predict. Her mother Sharon followed her with such a moving presentation that I felt duty bound to scuttle up to her afterwards to ask that she repeats this soul-warming dish for your delight next issue.

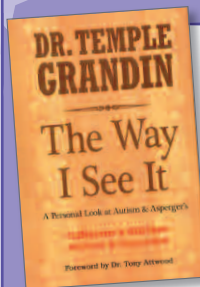
Our colleague Olga Bogdashina charmed delegates with a witty and fascinating insight into sensory issues and the day's programme closed with information technology pioneer Dame Stephanie Shirley.

There's so much more to be covered under this banner, but there was plenty to get the ball rolling here and an impressive array of techie stalls to keep the handsome delegate numbers happy.

Debbly Elley,
AuKids co-editor

Link to the best help and support

The website dedicated to making those helpful and sometimes vital links
www.autismlinks.co.uk



BOOK
The Way I See It (Hardcover)
By Temple Grandin
Published by
Future Horizons Inc.
£19.95
ISBN 9780986067310

It is hard to overstate Temple Grandin's influence on our understanding of autism. As well as the unique insight that only those on the spectrum can provide, she has read a phenomenal amount of academic literature and has also met and worked with huge numbers of others with autism, their families, teachers and carers.

This book is a collection of articles she has written for the Autism Asperger's Digest magazine since 2000. They're grouped into nine chapters covering a vast array of topics across the entire spectrum. Each chapter contains a new, updated introduction with additional information on the subject matter and references for additional reading. Temple has dedicated much of the past

30 years to understanding her condition and then translating it for the rest of us. This book is the culmination of that work, bringing it all together in one place to provide practical information that can be put to immediate use.

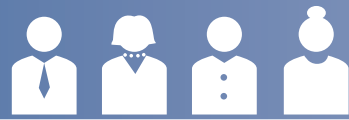
Although reading all 400 pages is a serious undertaking, each article is short and self-contained so it can be used a reference. I would highly recommend this book to anyone; even those who have already read lots about autism will be sure to find plenty of new information here.

A revised edition of this book is out next month, with 32 new subjects revised and expanded.

Mark Haworth,
AuKids Readers' Panel

Want to know more about this book? Read Mark's full review on our Home page at www.aukids.co.uk





“ Why does my son watch the same DVD episode again and again...and again?! ”

...AND THIS IS OUR AUTISM-FRIENDLY DVD PLAYER. IT HAS JUST THE ONE FUNCTION - REPEAT.



Chris Oliver

Professor of Neurodevelopmental Disorders, School of Psychology, University of Birmingham and Director of the Cerebra Centre for Neurodevelopmental Disorders.



Dr Jane Waite

Research Fellow and Clinical Psychologist, Cerebra Centre for Neurodevelopmental Disorders, School of Psychology, Edgbaston, Birmingham

Repetition of behaviour is part of the diagnostic criteria for autism spectrum disorders. Repetitive behaviour is an umbrella term that includes a wide range of behaviours including stereotyped movements, repetition of language and behaviours such as watching the same part of a DVD or TV programme over and over again.

There are lots of theories about why repetitive behaviour such as repetitive TV watching occur in autism spectrum conditions; however, to date there is no one theory that is ‘proven’ as researchers are still learning about these behaviours.

One theory with growing evidence is that a difficulty with executive functioning gives rise to these behaviours in autism. Executive functioning refers to brain based processes that help us to plan and regulate our actions and behaviour.

This includes our ability to inhibit (put the brakes on) behaviour, switch from one action or perspective to another action or perspective and hold chunks of information in our stream of consciousness for a task at hand. Difficulties with any of these brain based abilities are likely to lead to repetitive behaviour. For example, if a person has difficulties putting the brakes on their behaviour they may become ‘stuck in a loop’ and repeat the same action over and over again. If a person has difficulties switching their attention to another perspective or action they are likely to stay doing the same thing for a long time. Finally, if a person has difficulties holding information in their mind they may repeat/replay the information to help them process it.

It is also likely that routine and ritualised behaviour helps to reduce anxiety that some people with autism spectrum conditions feel due to the increased sense of security or predictability these actions give.



Dr Paul Holland

Paul Holland is a Consultant Behaviour Analyst working with adults with ASD in supported living. He also works privately as a Behaviour Consultant, Parental Coach and Trainer of Makaton, Autism Spectrum Conditions, (ASC), Communication and ABA.

This is an interesting question and one that I am sure the majority of parents of children with Autism Spectrum Conditions (ASC), have asked at some point. Children with ASC, and adults for that matter, desire structure and predictability in their lives so that they have a better understanding of what is happening not only now but next or later. Associated with this is the comfort derived from the known and the predictable.

If we consider ourselves for a brief moment; we also derive pleasure and

comfort from the known and predictable. Who enjoys walking into a party where they do not know anyone? Who proceeds with little or no caution or concern when asked to complete an unknown task at work? Very few of us...myself included. And in our case, we can communicate effectively, have a reasonable understanding of social etiquette and have multiple life experiences to rely upon.

Imagine what it must be like not to have these skills and abilities. So when our children choose to sit and watch a movie or cartoon it makes absolute sense that they choose to watch something (even if it is a single scene) that they know well, something whereby the story does not surprise or shock, that they can predict and therefore fully enjoy, that does not cause confusion, that they understand and can relax to.

Predictability and structure are very important to many people with ASC. We must always remember this. In addition whenever you are concerned as to the behaviour of your children or the people that you work with – stop and put yourself in the same situation and then imagine what it would be like with limited or no communication skills, a poor concept of social rules as well as other difficulties associated with autism. This will often help you to understand what is happening and why people with ASC sometimes behave in ways that seem unusual or that we cannot immediately and obviously understand.





Tom Bowes

My name is Tom Bowes, but if you are one of those people who likes to Google, try 'Autistic Genius'. I class myself as a public speaker, Vlogger and now a writer. I'm 26 years old and was diagnosed with Asperger Syndrome at the age 15/16.

Oh my goodness, that sounds like a lot of fun hearing the same sounds over and over again. I expect he also repeats what's said out loud, enhancing the symphony of repetition. As a 26 year-old autistic male, I still find myself watching the same silly YouTube videos as a form of comfort.

COMFORT - HOW IS YOUTUBE COMFORTING??!

When I feel down and out, my autistic brain automatically thinks of something funny to make me laugh. Sadly, according to the 'Triad of Impairments'* my brain isn't the most flexible - some might say a

tad rigid. So I am immediately drawn to something I have previously watched.

When I've had a horrible day, the concept of watching something without knowing how it's going to end is very difficult, because I have to take in loads of information without knowing what the important bits are. Also in theory it can take an autistic person eight seconds to process a new piece of information, so every time somebody speaks in a film or TV show, it could take me eight seconds to process. The problem is, the other characters also talk, which means that either my eight seconds of processing is reset or I miss information, and this makes me sad.

When I watch something that I've seen before, I can gain a sudden stim-fest which is a bit of joy and excitement with a garnish of relaxation. As I'm watching, it's like the air hugging me and is instantly soothing to my body. As I watch the video, I feel immense anticipation as I know every punchline and story development as it approaches. By the end, I can feel the anxiety fall off my body as I've been emotionally cleansed of the chaos from the neuro-typical world.

*The Triad of Impairments is a term that describes the key difficulties in autism - communication, social interaction and imagination. See 'What is Autism?' at www.aukids.co.uk to learn more.



Luke Beardon

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

Indulge me and imagine the following scenario:

You are 15 years old, English speaking, your parents have moved house; you are attending a new school. You are starting in the middle of a school term, you have no information about the school - literally, you don't know how many kids there are, not even if it's a single-sex or mixed school.

You don't know the layout, the timetable, the uniform, whether there is PE that day or what eating arrangements there are. Oh - and also the school is in France and you only know very basic French. However, you also know that there is a total expectation from everyone

- parents, teachers, students - that you will blend in the same as everyone else without any external assistance.

The only saving grace is that you *do* know that there will be a lesson at 2pm lasting one hour which is a written test, about English, written in English, to test English speaking capabilities.

So - how do you feel at 9am on the first day at this school? I suspect you would feel fairly terrified, and absolutely gagging for that 2pm lesson. There are a plethora of reasons why one might feel so stressed about this day, and many of them can be related to how an autistic person might feel - and, often, for much of the time.

One way of avoiding such stress - and a lot of it is related to a lack of predictability - is to create one's own stability and predictability. And just imagine that you have absolute capability of enjoying watching a TV episode every time you watch it... and each time you do, you learn its predictability a little bit more. You know what happens, in what order, the duration - and the pleasure of watching increases every time you watch it. What a bargain!

Please note: this is not the only answer to the question, just one suggestion...



Together for autism

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

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

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

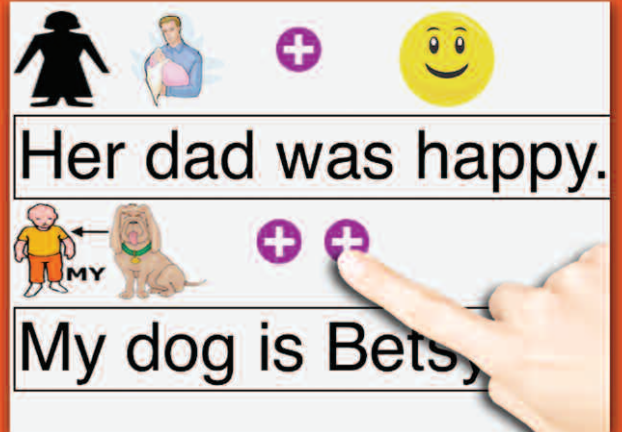
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Registered Charity number 209782



VISUAL READING (iPAD) READ WITH WORDS AND PICTURES



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www.visualreadingapps.com



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



STAR SPANGLED SPECTRUM



The UK takes its lead from the USA in many ways, so how is the States' attitude to autism shaping up? Do they really have all the answers when it comes to understanding the spectrum? We had a chat with a range of people living in America to see whether they felt the land of the free really is liberating for people with autism.



Jennifer Cook O' Toole is one of America's newest but already best-loved names in the world of autism; author of *The Asperkid's (Secret) Book of Social Rules*; *Asperkids - An Insider's Guide to Loving, Understanding and Teaching Children with Asperger Syndrome* and *Sisterhood of the Spectrum - An Asperger Chick's Guide to Life*, and an Aspie herself, she is also an international speaker. She lives in North Carolina. Her latest venture is a free YouTube vlog, *Speaking Geek*.



Kelly Conway is a speech-language pathologist working with middle and high school students (ages 11-21). She specializes in autism and augmentative and alternative communication in Philadelphia, Pennsylvania.



Based in Florida, **Lee A. Wilkinson** is a nationally certified school psychologist, chartered psychologist, registered educational psychologist and cognitive-behavioural therapist. He is also a university educator and trainer. Among his publications is the award-winning *A Best Practice Guide to Assessment and Intervention for Autism and Asperger Syndrome in Schools*. His latest book is *Overcoming Anxiety and Depression on the Autism Spectrum: A Self-Help Guide Using CBT*.



Nikki Mahoney is English but has lived in Seattle for almost 4 years. She is Mum to Mac aged 6 who is non verbal and Freddie who is 4 and verbal, both boys have autism.



Sharon Fuentes is the Co-Founder/Publisher and Editorial Director of *ZOOM Autism Magazine* (www.zoomautism.org - a free online resource) and 'the proud mother to an amazing autistic teenage son and an equally amazing neurotypical pre-teen daughter'. She lives in the Washington DC area.



Q For people with autism (and their families) who live in the States, what are the biggest challenges they face? What are the biggest benefits?

Jennifer: For families with youngsters, the challenge is finding the right school. For the kids, it's knowing when they need to ask for help. As I always say, you don't know what you don't know. Kids don't realise that their experience is different because of their autism, so they're not translating it to the teachers.

One of the things we need to teach our kids is not to be scared of who they are and learning to be able to explain their needs.

Nikki: The biggest challenges most people face I think are different coverage for therapies dependent on who you work for and which state you live in. For example, in California, ABA (Applied Behavioural Analysis) therapy is universally covered but in other states it is not. The biggest benefit I

have found is the amount of research and development that is happening in the US for autism.

Lee: There's a dramatic increase in the prevalence of autism spectrum conditions among children and adolescents - and the correspondingly large number of young people moving into adulthood has created an urgent need to address the challenges faced by many young adults on the autism spectrum.

Over a third of young adults with autism over here do not go into either employment or continued education between high school and their early twenties. Likewise, only about one in five live independently during this critical time.

It's crucial for our society that we create effective and affordable programmes adapted to meet the unique needs of about 50,000 individuals with autism who will leave school each year.

On the plus side, cooperation and

collaboration among families, researchers, professionals, and government agencies in the US have produced significant progress and benefits through science and advocacy. About \$1.5 billion has been dedicated to autism research over the past 5 years. This investment has translated into advancements in research and applied practice.

Kelly: I think the biggest challenge is acceptance. Quite often people don't understand autism and some parents end up feeling alone or isolated. Autism is in the media, but it only gives snapshots of life. The reality is not always clearly depicted.

Sharon: There are disparities in autism awareness, acceptance and access to resources across the United States; especially among the minority populations and lower economic class. In addition, there are not enough trained professionals to offer services to the growing number of children and adults who need them. In many cases insurance does not pay for those services they do find... even in states that have passed laws requiring health insurance to cover them. The end result is huge waiting lists to get governmental support.

One of the things we need to teach our kids is not to be scared of who they are and learning to be able to explain their needs..
Jennifer



Q What do you think the overriding attitude to autism is in America?

Jennifer: Misunderstanding. The hardest thing that I think about being on the spectrum is that relentless 'how can you be so smart but be so stupid?' People on the spectrum have an intuitive understanding of each other. Like the ice-cream sundae, we have all the same ingredients, just different strengths of them. They can often see the needs in each other that neurotypical people can miss.

Nikki: That very much depends on where you live in the US but I have found it to be less of a taboo subject. People love to talk about

The current trend in the United States is moving away from just being aware of autism and stepping closer to becoming a culture of acceptance.

Sharon

their feelings here so I never feel like I'm wasting anyone's time.

Lee: Americans are very concerned about autism. They believe that autism research should be given a much higher priority and would like both government and the private sectors to increase research funding to develop more effective methods of diagnosing and treating autism. There's also a hunger for more credible, reliable and in-depth information about autism from reliable resources.

Kelly: Although people are aware of autism, they often aren't aware of the day to day needs of families over here. I recently read an article that stated that research needs to shift its focus from finding a cure towards how we are educating individuals on the spectrum. I agree with that.

Sharon: The current trend in the United States is moving away from just being aware of autism and stepping closer to becoming a culture of acceptance. This new way of thinking has come about mainly because of the incredible efforts from disability rights organizations like the advocacy group The Arc, Autism Society of America and ASAN (Autistic Self Advocacy Network) that are ensuring that the voices of autistic people are heard in policy debates and the meeting rooms of power.

Q What are the differences between the UK and America when it comes to autism?

Jennifer: I've found in England, Ireland and it was also true in Denmark, people say 'Oh, you're so much more progressive...etc'. I think it's a little bit of the grass is always greener, because I honestly don't think that's necessarily true. What it comes down to is that we all want to believe that there is a place after which we can model ourselves. It's not that we're necessarily better at things; the difference is that Americans are more comfortable showing and discussing their emotions. Also, until you are here you cannot conceive of the size of where we are. The reason you've heard of public figures in the States is because the pool is that much bigger, not because the culture is that much more ahead.

Lee: We have common problems in both countries. Schools in both the US and UK share the challenge of providing appropriate services to a diverse and increasingly large student population diagnosed with autism.

In America, the Individuals with Disabilities Education Act (IDEA) is the federal special education law that ensures public schools meet the needs of students with disabilities. It specifies 13 categories of disability, including autism, to determine eligibility for special educational services.

The UK's equivalent SEND Code of Practice does not define categories

of special educational need. In the UK, broader areas of need are described, such as social, emotional and mental health difficulties.

Research suggests that schools in both the US and UK are not adequately equipped to teach or provide services to children and young people with autism spectrum conditions. Although teachers are receiving some specialized training, there's a pressing need for more education opportunities and improved preparation.

Q What do you think America does well when it comes to autism and where do you think improvements could be made?

Jennifer: Things are improving. It's a little bit less swept under the carpet now – a *little* bit! Because of social media, there is more dialogue happening which does reduce some of the stigma.

I think overall we can equate this with a Civil Rights movement. If you look at the gay rights movement – not very long ago, within our lifetimes, the diagnostic manuals called that a mental illness, and later not an illness but a difference and then it goes to tolerance (which I always think sounds like a headache) and then into awareness or acceptance. I think the same thing is happening with autism, if we can follow that trajectory that would include everybody around the world.

To improve, we need to embrace the idea that before you're on the autism spectrum you're on the human spectrum and that everything that's good for autism is good for everybody, but it's more essential for people on the spectrum.

I'm working on a memoir for mainstream publication because so far, for girls on the spectrum, Temple Grandin is the only high profile woman they know of with autism. I know her very well and she's awesome, but she and I could not be more different personality-wise. To see that is important for girls. We need positive and diverse role models.

Nikki: I think the therapies the children have received here have

been second to none in terms of using the latest research and constantly moulding the therapy to the children. I think the US needs consistency in what is available, though.

Lee: Research initiatives throughout the US are playing a central role in efforts to advance our understanding of autism, improve diagnosis, and promote good practice.

For instance, The National Autism Center (NAC) and The National Professional Development Center on Autism Spectrum Disorder (NPDC) have identified interventions with the most scientific evidence shown to be effective and produce positive outcomes for children and youngsters with autism.

So, people now have more up-to-date information and resources and can make more informed decisions on interventions.

We now need to address the mental health issues of adolescents and adults on the autism spectrum. Research indicates that a significant proportion of adults and teens experience psychiatric conditions, such as anxiety and depression. Accessing services to address these symptoms presents a major challenge.

We also need to expand our understanding of how cultural and linguistic diversity impacts on identifying autism and treating it.

Kelly: We have amazing programmes for children with autism in the United States. We need to start focusing on the future because as this generation of children transition from school to adult/work life, we are finding programmes are few and far between. Transition to adulthood at age 21 leaves few options for young men and women with autism and it causes a lot of stress on the family.

Sharon: We have many incredible autistic activists such as Temple Grandin, John Elder Robison, Jennifer O'Toole, Stephen Shore, David Finch, Barb Rentenbach and so many more who are personally doing everything they can to educate communities and improve public perceptions of autism.

I think we would be much further along if we actually listened to these folks more and realized that those who are autistic are the true experts on autism.

We would be much further along if we actually listened ...those who are autistic are the true experts on autism.

Sharon





Santa's Gone Autism-Friendly

It's the time of year when your relatives ask you for ideas for presents that will delight and entertain your child. Unfortunately, the sorts of things that delight and entertain (licking windows/bouncing on furniture/opening and shutting cupboards) aren't always readily available for autistic kids. Here, we've picked some great toys that we've tried out ourselves. If you're anything like us, you'll end up surfing some of these websites and find tonnes of other ideas besides. Happy shopping!

1. Laser Star Projector

This mains-powered laser light projector is Awesome with a capital 'A'. It creates a beautiful green universe of moving stars and cloud formations. You can choose an adjustable blue 'space cloud' to have against it, or just pitch black. It's swooningly relaxing and very robust. A very good sensory addition to any bedroom (can be wall mounted).



Where from? We found a good-value one for £89.99 at Find Me A Gift (www.findmeagift.co.uk)

2. Magic Power Ball

A mesmerising display of multi-coloured, multi-pattern spinning LED illumination.



Where from? Explore Your Senses www.exploreoursenses.co.uk at £9.95

3. Flufflings Twirl and Whirl

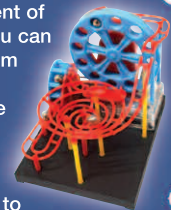
Reader Sara Basma said this frankly barking mad creature had her son captivated as it twirled around making silly noises. It does have an off button...



Where from? £9.99 at Toys R Us.

4. Amazeballs Marble Runs

We found these lurking in the toy department of Selfridges but you can also get them from Amazon. For children who love watching marble runs, this is an exciting desktop game that's cool to have whatever your age. There's a range of them, but the fairground wheel is the one we like best. Bear in mind that some of the plastic bits are quite delicate and removable. You'd do well to stick everything in place.



Where from? Amazon at £11.92

5. Kaleidoscope Lamp

This is operated by 3 x AA batteries (included). The crystal globe rotates creating patterns of bright coloured light Disco!



Where from? Explore Your Senses www.exploreoursenses.co.uk at £12.95

6. Little Live Pets Bird Cage

Interactive toys are great for kids; they reward communication attempts in a way that no human being can! This pet bird loves a lot of attention, as it sits or swings on its perch. When it's very happy it'll even whistle you a special tune. Best of all, it can record ten seconds of your voice and talk it back to you. Needs 2x AAA (not supplied).



Where from? John Lewis at £19.99

7. Pac-man Ghost Light

A colour-changing sensory lamp that is also cool as heck. It phases through 16 colours and has a flashing party mode which changes colour to the beat.



Where from? www.firebox.com firebox £19.99

8. Waterfall tube

Turn the waterfall tube to see hundreds of tiny coloured balls and tiny, rattling ball-bearings cascade to the bottom over a sequence of platform obstacles.



Where from? Explore Your Senses www.exploreoursenses.co.uk at £9.50.

9. Light Stax Light Up Building Block

These launched in 2014 and are illuminated construction blocks that use LED technology, but are still 100% compatible with existing traditional building blocks. Each Stax magically lights up as it is connected to a power base or any lit Stax. No special connectors or wires are needed. Just stack them and they light up!



Where from? We found a 36-piece classic pack on Amazon for £27.30. You can also buy them at Selfridges.

10. Infinity Light Up Spinning Top



The Infinity Light Up Spinning Top has 32 different light patterns and can spin forever! Encourages tracking skills, requesting and hand-eye coordination. Uses 3 x AAA 1.5V Batteries (included). Surf the Sensory Toy Warehouse online for hundreds of similar toys for sensory seekers.

Where from? www.sensorytoywarehouse.com at £8.29.

11. Sensatrak Inflatable Wheel

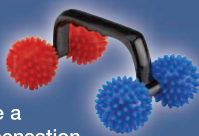
Just the slightest movement inside the air-filled Sensatrak tube provides children with a variety of motor and sensory input while challenging their balance. Rhythmic rocking calms and provides relaxation. The bouncing, rotation and shaking can provide sensory input. Gentle bounces feel like a floating trampoline. Reader Karen Sweeney says her daughter Phoebe loves hers! Measures 96cm diameter and comes with foot pump.



Where from?
www.cheapdisabilityaids.co.uk at £39.99 (at the time of publication - down from £80).

12. Four Ball Massager

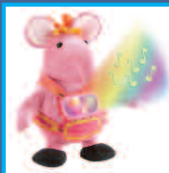
Roll the four hard spiky hedgehog balls over your body to receive a unique tactile sensation.



Where from? Explore Your Senses
www.exploreyoursenses.co.uk at £8.95

13. Clangers Lullaby Starlight Tiny

Tiny Clanger is the perfect bedtime companion for your young one. Press Tiny's tummy to play soothing music and to shine a gentle starlight that gradually fades over 20 minutes.



Where from? Toys R Us at £24.99.

14. Classic Giant Wind Ups

A number of these are available – Mortimer the monkey, pictured here, (22cm); Christopher the soldier (26cm) and Merlin the robot (22cm). They're classic clockwork toys – but giant!



Where from?
Available from Toys R Us and on the same site online (search under the brand Z-Windups). Prices vary from £9.99 for Christopher to £17.99 for the robot. You can get them on Amazon but availability varies.

15. Marble Run Super – Bright Minds

A sturdy marble run made from quality plastic and capable of working in many different combinations. Set includes paddles, launcher, sky runs and bridges. 102 pieces.



Where from?
www.brightminds.co.uk at £29.99

16. Light and Action Building Set



A gears set with 121 durable plastic gears, a power motor, flashing lights, glow in the dark stickers and more - all in a handy storage tub. Great for those who like motion and light and a lovely game to play together. Button cell batteries included. Requires 3 AA batteries, not supplied.

Where from?
www.brightminds.co.uk at £49.99

17. Atom Massager

Great for sensory input, the highly stimulating effect of this massager has also been known to provide pain relief in some individuals with autism. It lights up and spins around on its feet if you put it on a flat surface.



Where from?
www.specialneedstoys.com/uk/pro-prioception/vibration/atom-massager.html - £9.50 excl VAT.

18. Take-N-Play Thomas & Friends

Collect Thomas, Percy, Diesel – or stack all three!



Stackable spiral track is stored inside the hill it's built on! Compatible with other Take-N-Play kit.

Where from? Tesco at £11.

“When I lived at home, we all struggled to cope. Now I love spending time with my family”



At Hesley Group we know being a parent of a child with autism and complex needs can be challenging. We also know the decision to entrust their care to someone else can be one of the hardest a family will ever make.

That's why when children come to live with us, nurturing the family bonds is all part of the plan – regular, high quality contact supported by a team of professionals who know, understand and value the need for a family to be together.

And, over time, the story gets better and better - settled, happy and able to enjoy being with their family, children we have the privilege of looking after can start to reach their full potential.

To find out more about how we make a big deal about quality family time visit www.hesleygroup.co.uk or call 0800 0556789.

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Established in 1975, the Hesley Group provides specialist support through its schools, colleges and adult residential services with a highly experienced and expert multidisciplinary educational, care and therapeutic staff resource, in high quality purpose built settings. We're focused on positive outcomes and progress towards sustainable independence.

19. Star Projector Cube

The Star Projector Cube has a choice of either lullaby or nature sounds to relax to. It turns a ceiling into a soothing night-time stary sky scene of changing colour. Select the sound of your choice or 'shuffle' mode, options of sound only, light only or both. Sound will automatically turn off after around 15 minutes. Uses 3 x AA batteries (not included). Mains adapter facility (adapter not included). Lasted well when we tried it and was much loved.



Where from? Sensory Toy Warehouse at £19.99

20. Mega Flashing Orbit Ball

This large tactile colourful ball is malleable, squishy and lights up when bounced.



Where from?
Explore your Senses
www.exploreyoursenses.co.uk at £5.95

WIN TOYS GALORE!

Waterfall Tubes and Star Projector Cubes Up for Grabs!

AuKids has bagged 3 x waterfall tubes from Explore Your Senses and 2 x Star Projector Cubes from the Sensory Toy Warehouse. Just email your name and address to us at competitions@aukids.co.uk with either 'waterfall' or 'cube' in the subject header. You can also enter by post to AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE. Winners will be selected at random after the closing date of November 30th 2015.

Note: Please note, AuKids is different from lots of other places. Some other magazines feature stuff that they 'recommend' because they've just received a press release on it, or because someone has paid for the space. These toys are featured because we like them.

Most of these items are available at more than one store, we've just featured where we found them. Prices were correct at going to print but may have changed since.

The Language Layer Cake

In normal language development, words seem to appear almost magically. One minute they aren't there - the next minute, bingo! Speech seems so simple, it's easy to forget the amazing process that goes into it. So what do our autistic kids need to conquer before they can speak? Inspired by Bake Off, we've made our own layer cake. Start at the bottom and work your way up...cup of tea, anyone?

P.S.
This is a simple recipe and these are basic ingredients, not all of them by any means.

Speech is what we wait for, the attractive and visible part of our language cake. But it is only the superficial topping of a complex language system. Speech is merely the motor process by which we articulate a sound to make a word. It isn't the same as language, which is assigning meaning to a sound. Although we really like the icing, it's the cake (language) that counts. If we're lucky, the icing will come in time. If not, the cake, if it's a good one, can be just as satisfactory on its own!



SHOW-STOPPER: Speech

Sometimes in autism, messages get scrambled between forming in the brain and being pronounced. This can happen in the early part of the message's journey, or in the very later stages of its journey, where the mouth, tongue and lips struggle to sequence sounds properly (this is known as verbal dyspraxia).

TECHNICAL CHALLENGE: Coordination

For an autistic person, being able to generalise may be difficult, so something learnt in one context can't always easily be transferred to another.

BAKING FOR THE OCCASION: Generalisation

Autistic kids have difficulty processing language. They may have to hear a word four times as much as anyone else in order to understand it.

NOT SUCH A SPONGE: Understanding

To process language, we have to accurately listen to and interpret it, before assigning a meaning to it. This means we filter out background noise and attend to voices. Kids who have sensory processing difficulties (SPD) as part of their autism have less ability to filter sounds that aren't voices.

SIEVING WITH CARE: Filtering

To understand words, you need to make the correct connections. You have to know that the thing someone is pointing at has a name. Assigning random sounds to an item is an abstract concept, and autistic brains struggle with abstract ideas.

THE SAME RECIPE: Joint Attention

For most of us, the motivation to communicate comes naturally. But as the motivation to speak is social, it may not come naturally to people with autism. This is why any sort of attempt at communication - even troublesome tantrums - should be viewed as a message to be decoded.

CAN'T COOK, WON'T COOK: Motivation

Feel free to share our Language Layer Cake, but please note that the idea is copyright AuKids magazine, so mention us when you do.

BLOGDASHINA



Olga Bogdashina is an internationally renowned researcher and lecturer in autism and the author of books on sensory perception, the Theory of Mind, communication and spirituality in autism. Her autistic son Alyosha, 26, is the inspiration behind her career.

A paper blog by autism expert Olga Bogdashina

Blog 3: Not Such A Bonding Experience

In many books about autism, there are sections on 'challenging behaviour'. It's defined as self-injury, running away, hitting, kicking and other physical outbursts.

This has to be dealt with for the sake of both the child and those around them. However, the way these behaviours are interpreted is often misleading.

I've read reports about my son's behaviour at school and in many of them there were descriptions of 'aggressive outbursts'. Yes, on the surface he seemed aggressive - lashing out at people or attacking the furniture - but he was actually suffering as much as his 'victim'. He cried and apologised ('I didn't want to hurt you') and I knew he was telling the truth; he had no intention to harm anyone. His aggression indicated that he was not coping and was not in control of his actions.

Autistic children are very easily overloaded in situations that are 'normal' for others. They can't filter the same amount of sensory stimulation and are drowned in all the sounds, sights and smells that seem to 'attack' them from all directions.

In order to protect themselves, they may either shut down (to get a break from the hostile environment) or continue to try and process all the incoming information, despite an inability to keep up with it. This results in hypersensitivity and/or fragmentation (only seeing parts, not a whole image) that eventually brings with it anxiety and confusion. It can of course lead to meltdowns and difficult behaviour.

Here is a paradox: these 'difficult' children are doing their best to

communicate with us. If we look at it from this perspective, so-called 'aggressive' behaviour can often be a positive sign.

Those who work with so-called 'withdrawn' children know how hard it is to reach them and involve them in any activity. These children seem very happy in their own world and are not motivated to reach out. In contrast, those who we call 'challenging' (and even aggressive or violent) are *highly* motivated to be part of their society. As one of my friends with autism (who is, in reports, 'prone to aggression') says: "I've always wanted to fit in, to belong to my family, to our community, to the mainstream society. I wanted to do everything others did, despite my restrictions (being easily overloaded in crowded places and intolerant of noise). Well, in many cases it didn't work. It's very frustrating."

people crunching popcorn in the seats next to ours... I knew my boy wasn't coping; he was kicking the seat in front of him and shouting "Stop it!"

He needed to get out as soon as possible, but my suggestion to leave was met with loud protestations: "No, no, no! I want to watch it. We are a family!"

The situation went from bad to worse with help from the audience. There were two battles going on, here - one between James Bond and his rival Gustav Graves; the other, between me and my son. For some reason, people in the cinema were much more interested in the outcome of the latter (perhaps because they were sure that Bond would win anyway).

I tried to persuade Alyosha to go out by promising everything under the sun (starting with ice-cream and

ending with a trip to Mars), while attempting to minimise the damage caused by his 'aggression'. Eventually, I succeeded. Once we were outside the building, we were both crying, my son sobbing his remorse and me blaming myself for exposing him to this torturous environment.

It is important to remember, that when an autistic child exhibits what looks like aggression, it does not necessarily mean that it's malicious behaviour. Often it just reveals that they aren't coping and aren't in control of their actions.

If we view it as a form of communication (when other forms of communication are no longer at a child's disposal) we all stand a better chance of success.

EDITORS' NOTE: Thank goodness we now have autism-friendly screenings! See advert below.



I can relate to that, as I see how desperately my son wants to participate in whatever we do as a family. To help him, I started a desensitisation programme when he was very young - exposing him to many experiences in small doses, giving him power to control his environment. That is, how much of the stimulation he could cope with and how long he could tolerate it for.

It worked and in a few years we were able to go to many different places and enjoy many activities together.

Despite this, I've made a few (okay, quite a few) mistakes along the way.

For example, after he'd enjoyed Harry Potter and the Philosopher's Stone at the cinema (quite a long movie), we decided to go and see Die Another Day with Pierce Brosnan - a decision I regretted 40 minutes into the film.

The sound was too loud, there were flashing images on the screen,

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MISSION IMPROBABLE?

Many of our readers are parents who also run an autism-related business or service. Are they mad? Do they have too much energy to burn? Or is it simply that they're passionate about making a difference to people in the same boat? We wanted to know how they manage to juggle their home lives with a very personal, but professional, undertaking.

TALL ORDER: Running a company and bringing up an autistic child was about as easy as levitating whilst filling in a Carers' Allowance application form. Actually, the levitating was easier.



SEW FAR, SEW GOOD...

Amanda Bland, A Stitch Different

A Stitch Different is a small company selling bespoke handmade weighted and sensory products. It was set up by Amanda Bland, mum to a 19 year-old son with ASC. www.astitchdifferent.co.uk Call 07525 494205.

I found weighted products from major suppliers expensive and the choice limited, so I just started making my own. Firstly I made them for friends' children, but word spread and because I could make products that were affordable and bespoke, I started getting orders.

"Because I could make products that were affordable and bespoke, I started getting orders."

My caring role became more demanding and the business grew very fast, so I approached my friends Steph Thomson, Sara Walsh and David Lund to help out. Sara and Steph are also parent-carers of kids with autism. David's business



PARENT POWER: Amanda Bland, Steph Thomson, Sara Walsh & David Lund of A Stitch Different Receiving the Community Focused Business of The year 2015 Love Barrow Award

background makes him invaluable.

A Stitch Different is a Community Interest Company (CIC). Its aim is to help local people living with autism and other disabilities by providing employment. With the help of a new Lottery grant, we have bought machinery in order to deliver sewing workshops to young people with disabilities as well as their parents and carers.

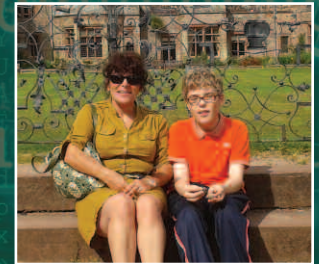
We now have several young people with autism who help with manufacturing and some parent-carers working for us. Our latest product is the Stitch Body Sock, a fun Lycra sack that gives sensory feedback.



EQUAL TO THE CHALLENGE

Geraldine Hills, Inclusive Choice Consultancy

Geraldine's son Sam is 14 and has a condition called septo-optic dysplasia and Tourette's syndrome. Inclusive Choice Consultancy provides training on the Equality Act and inclusion for parents and professionals. See www.inclusivechoice.com



INCLUSIVE CHOICE
CONSULTANCY

The experience of winning an education tribunal after a school had discriminated against my son ignited my passion to understand the Equality Act. My goal became to help other families going through similar situations. I started up my own company from my bedroom on my laptop and over the last eight years have grown that business.

"The biggest lesson I have learned is no matter what you're doing you must always try to look after your mental wellbeing and emotional resilience."

Sometimes it feels like I must have been mad to start up Inclusive Choice Consultancy, especially when I am trying to juggle both my professional and

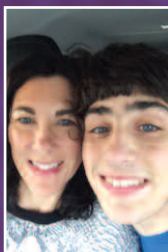
home life, which has been quite a challenge in itself. In the early days, I used to think I had to control everything, but now I have learned to ask for help when I need it and accept it when it's offered. Some days are good and passion comes naturally. Other days are tiring and discouraging, but that's life in general - so I just keep pushing on, doing what I love.

The biggest lesson I have learned is no matter what you're doing you must always try to look after your mental wellbeing. I have written two books on emotional resilience: *Second Chance Day* (for adults) and *Second Chances* (for young people, co-written with young people). Both are now available on Amazon.

MOVE OVER CRUISE, TOM TAG TAKES OVER!

Clare Cusack, Orkid Ideas

Clare invented TomTag, a simple device helping autistic children to plan for the school day. You can buy TomTags at www.orkidideas.com



Whilst studying with Dyslexia Action, I designed the original TomTag which was a bag-packing

checklist to help students prepare their things for school. My son Tomas, who has autism, was the inspiration for TomTag. Many nights spent printing, cutting and laminating pictures to make visual learning aids for him made me determined to turn the concept

"I approach my life in terms of a bike ride in the Pennine hills: lots of ups and downs but remember to stop regularly to appreciate the moment!"

into an accessible product for others.

The TomTag has since evolved into two ranges: the 'I can do it' sets teach a range of self-help skills and the 'I know what to expect' sets offer visual schedules for home and school.

Running a business, raising children and maintaining a house is a constant challenge! The flexibility of working from home and near to my family helps, as Tomas still requires a high level of support. I approach my life in terms of a bike ride in the

Pennines: lots of ups and downs, but I enjoy the journey and remember to stop regularly to appreciate the moment!

Receiving wonderful feedback from customers keeps me motivated. I also know a few mums who would like to get a TomTag for their husbands too! Watch this space!



STAR OF THE SMALL SCREEN

Gareth Child, ASD Friendly

In 2003 Gareth, whose son Ned has autism, re-trained as a special needs teacher and specialised in autism and challenging behaviour. After medical retirement in 2013, he now works part-time supporting adults with learning disabilities. Gareth and his wife Michaela founded www.asdfriendly.org in 2003.



In 2001, Helen Rogan took her autistic son, Mark Owen, to Hownsgill Viaduct in Durham and jumped.

"At its heart ASD Friendly is about overcoming the alienation that so many parents can end up feeling."

A week later our son was diagnosed with autism, and we could see the viaduct from our home. We knew just how little support there was and how desperate parents like Helen could get.

Michaela and I had spent a decade running a variety of Internet forums. We were used to organising groups of tens of thousands of people, so we set up a new one.

We wanted to create a place where parents could share experiences and support each other, and it worked beyond our

wildest dreams. We ended up with a global network of friends to turn to, with shoulders to cry on, helpful advice - and wine recommendations!

More than 20,000 people have used ASD Friendly and it only takes an hour or two every day to administer it. We have had special events including professional training, family days out at London Zoo, the National Railway Museum, and Legoland, as well as nights out for parents. At its heart ASD Friendly is about overcoming the alienation that so many parents can end up feeling. Autism families - you are not alone. It helps to know a few thousand people are only a click away.

Much of ASD Friendly's activity has moved to Facebook now and it is a group of real friends. We're watching children grow up and achieve things we never believed were possible 14 years ago. That's the happy ending all stories should have.



A SEAMLESS TRANSITION

Mel Thomsett, Sensory Smart Store

Mel Thomsett runs a UK-based online company dedicated to seamless clothing for those with sensory sensitivities. Find it at www.sensorysmart.co.uk. Her son Archie is 12 and has autism including sensory processing disorder (SPD).

I really struggled to find work that fitted in with Archie's care needs and endless appointments and it felt like everything was against me getting back to work.

Archie has sensory processing disorder and when we found some 'magic socks' available in America with no seams or bumps to irritate him, it was such a game changer - such a small

thing! I figured if we needed them, others might, and out of this The Sensory Smart Store was born.

"The more of us who share successes and help, the easier the path for those who follow behind us."

Along our journey we've found new products that helped us personally and made them available to others. In this way, we grew organically. Now we have the most amazing tribe of customers who are really engaged and involved in shaping the future and direction of the store and what new products we

seek out. Just this week, a mum living in Poland has found something fantastic and sent it to me to investigate.

Parenting a child with autism is such a huge journey and you learn so much, I did feel some responsibility for passing knowledge on. This can be a tough path at times...the more of us who share successes and help, the easier the path for those who follow behind us.

Last year, Archie refused to go to school for months and there was no budging him no matter what we tried. Suddenly, I was back to full-time caring. But on the really tough days (I don't have to tell you about those), the wonderful e-mails, letters and updates we got from our 'tribe' powered us on. I now have Helen working with me who is a gem and have



Sensory Smart Store

managed to get Archie into the right school (what a battle!).

So now we are back to business and have some amazing projects in the pipeline. Now I couldn't imagine doing anything else - who'd have thought it?!

ACTING ON HER INTUITION

Penelope Robinson, Five Towns Superstars

Penelope's initiative, Five Towns Superstars, is a drama group for autistic youngsters based in Staffordshire. www.fivetownstheatre.org.uk/superstars

My son is ten and has multiple diagnoses including autism. Having watched me perform on stage many times, he wanted the chance to join me in a musical.

The production team at Five Towns Theatre in Newcastle under Lyme had to make many adaptations whilst supporting and celebrating with me and my family. This experience made us all realise that there was no provision like this specifically for children with autism available in Staffordshire.

After a few exciting (and sometimes stressful) weeks, we launched Five Towns Superstars, based at the same theatre. We provide drama activities especially for autistic children who might otherwise not get the opportunity. As well as supporting them, it raises autism awareness within the local community.

We have watched our son make friends, gain confidence, learn new skills and be excited about something other than Minecraft! I just want the same as other

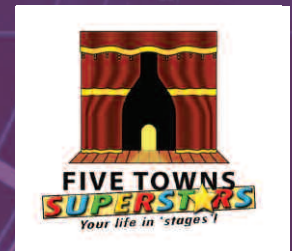
"I just want the same as other parents of kids with autism; understanding, acceptance and support."



ON WITH THE SHOW: Keith Ragdale, Penny Robinson, Hayley Parsons and Ed Costello help put Staffordshire stars on the stage

parents of kids with autism; understanding, acceptance and support. Superstars is a way of achieving that.

I had struggled to find a job that fits around my unconventional life. For a while, my husband and I had to balance his job with my drama degree whilst caring for our son and compiling evidence for his Statement! This job has given me the chance to combine my love of acting with my previous career in childcare - and take my family to work with me. Not many people can say that!





The Last Word

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

Can You Spare a Moment of Their Time?

If you have an autistic child, the chances are that you concern yourself with child development slightly more than the average parent.

I think it's fair to say that during the summer holidays, other kids are sometimes left to languish over Monopoly and Nintendo. Boredom, after all, is hardly a disease.

As autistic kids are sometimes not as proactive as others when left to their own devices, though, boredom can feel rather threatening.

I've always tried to protect Bobby and Alec from the discomfort of boredom. Even when they were babies, it would take a snow plough to remove the toys from our lounge at the end of the day.

As our twins grew, big old Boredom became an enemy to be defeated. As they weren't interested in the usual types of play, I adopted the role of court jester, conjuring up activities in a fun-filled timetable until I was exhausted. Mainly, this was from tidying up stuff that they weren't that interested in to start with.

Of course, boredom isn't a state we want our kids to be in permanently, but I no longer see it as quite the adversary I used to. Too often we project our neuro-typical way of thinking onto our autistic kids. But empty time doesn't necessarily equal boredom, even though we may think it. When you have a hard time processing your environment, some empty head space may be just the ticket.

I've learnt that Alec – (my non-verbal 11 year-old) – can actually be resourceful if given a little bit of boredom. Okay, so he's not building the Eiffel Tower with Meccano, but

during one spare afternoon he placed building blocks in a cardboard lid and shook them before trying different shapes to observe the auditory effect. When I joined him in this scientific game, we ended up trying all sorts of sounds before building towers together. On another afternoon, Alec emptied all toy boxes so that he could gather his vehicles together for a sort of impromptu convention. This was categorising. And (apparently), this was fun. Critically, it was his idea, not mine.

Bobby, my 'mainstream' verbal twin, spends way too much time on the computer, but when I took the time to watch what he was doing, I realised that it wasn't repetitive at all. Some of it was programming, and at other times he was playing 'Hide and Seek' and virtual 'Simon Says' using Minecraft. It isn't physical, but it is social – a virtual playground. When I start to think 'I couldn't spend all day on the computer,' I realise that in fact, I regularly do!

Back in the Seventies, I remember being particularly bored during the school holidays (we didn't have Nintendo and my older brother was a bit too good at Monopoly) and I would spend a lot of time hearing the phrase 'find something to entertain yourself with'. Aside from rubbish attempts at cooking fairy cakes, I wasn't very good at doing this.

This is perhaps why I have had a hard time as a parent learning that kids, even autistic ones (and sometimes, particularly autistic ones) NEED a degree of boredom.

After all, initiative requires boredom to thrive.

Cover Star

★ Yusuf Yakoob ★

Age: 5 **Diagnosis:** Autism
Lives: Heald Green, Cheshire
Loves: Outside play, soft play, bikes, making friends, miniature toys, Marvel characters.
Dislikes: Nothing – he loves everything ☺



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The Autistic Snowman



Watch it, I hear it's not pretty when he's having a meltdown.

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