

Autkids®

Positive Parenting for Children with Autism Spectrum Conditions



Blinded With Science

What should we believe about autism?



Cyber Mentor

Keeping your junior technophile safe!...



Get Image Conscious

Making visual support work at home



WIN

A sensory tent and toys worth over

£150!



Letter from the Editors

Debby Tori



Hi and welcome back to AuKids for the autumn!

Your Own SLOGAN Added to Our Range!

Our T-shirts have gone down a storm, and with caps, book bags and pump bags added to the range, our kids are looking great!

Now there's a chance to create your own prize-winning slogan for the quirky AuKids collection at www.finsdesignandprint.co.uk

There are two categories:

CHILD CATEGORY

Dream up a slogan that kids can wear on an AuKids' T-shirt.

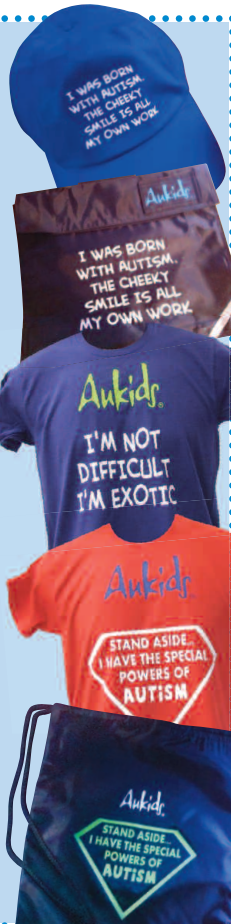
ADULT CATEGORY

Think of a slogan that adults who work with children with autism can wear. Remember, keep it simple and positive!

One autism slogan from each category will be added to the collection and winners will receive a child's T-shirt and bags for the kids' slogan and adult T-shirt and cap for the adults'.

No designs please, although you can make suggestions for simple symbols to accompany wording.

Winners will be announced in our January issue. The closing date is December 1st 2013. Send them to aukidsmag@gmail.com stating clearly in the subject header 'kids slogan' or 'adults slogan'.



As usual, so much to squeeze in and so little space...but not for much longer! From January 2014, AuKids will be increasing in size by four pages. This doesn't sound like much, but when you consider that it's a third of the magazine's current size, and when you also consider how much content we can pack into a small space (the editorial equivalent of 50 elephants in a telephone box), then you should be as excited as us.

Why have we done this? Well, we took the hint. Our readers always say great things about AuKids, your only criticism seems to have been that there isn't quite enough of it.

Of course, we have to somehow pay for the cost of extra pages. Postage costs have also risen since we launched 5 years ago. This means AuKids will now be £15 for an annual subscription. Still reasonable, we reckon – and we hope you feel it's worth it. Current subscribers won't be charged any extra until renewal. So if you're one of the organised ones who bought themselves a three-year subscription recently, you're allowed to feel quite smug.

You probably don't need reminding that AuKids is not-for-profit and the subscription fee just covers our costs.

In other news, we'd just like to thank all of you who wrote to tell us how much you liked the Autism Sundae Dessert feature. We were quite overwhelmed with your responses.

One reader wrote: *'I am going to keep this article in my bag and produce it as often as possible. It is a work of pure genius. I have read so many books and blogs etc. but this is the best and most simplified version I have ever read. Thank you thank you thank you!'*

We particularly liked the 'work of pure genius' bit.

As always we'd like to thank our graphic designer Jo Perry for bringing our ideas to life, which was particularly important for the ice-cream sundae article.



SWEET SUCCESS: Our Autism Sundae Dessert feature

In fact, you liked the ice-cream sundae feature so much that we've printed a very limited edition of it as an A2 poster. If you'd like one, send us a cheque for £9.70 (includes P&P) payable to AuKids magazine to AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE. If you want to avoid postage costs and collect one from our office in Cheadle, Cheshire, the price is £6.50 and e-mail aukidsmag@gmail.com to arrange collection. Only 25 copies available so first come, first served! Write your address and phone number on the back of the cheque plus the word 'poster' at top left hand side of the envelope.

Tori & Debby

e-mail: aukidsmag@gmail.com

COMPETITION WINNERS FROM ISSUE 20:

Katherine Gibbinson, Essex; Jo Sampson, Bristol; Jill Hampson, Liverpool; Afshin Tirmizi, Basingstoke; Nicola Naylor, Warwickshire; Sophie Page, Hatfield and Batsheva Kaye, Manchester.

EDITORS:

Tori Houghton and Debby Elley

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Front cover photo taken by Nikki Sheppard, keen amateur photographer and Dad to our front cover star Will. To see more of Nik's photography go to: www.facebook.com/mowburntphotography

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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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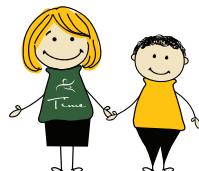
Time Specialist Support is Recruiting in Manchester and Chester!

We specialise in supporting and befriending youngsters with autism spectrum conditions.

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- ✓ Oodles of enthusiasm?
- ✓ A passion for autism?
- ✓ Good organisation skills?
- ✓ Over 12 hours spare a month?

It could be you!



Time Specialist Support

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**A Star
Prize Worth
£150!**

Mum Vanessa Bell recognised a need for resources and decided to do something about it herself. Her company Starpacks (www.starpacks.co.uk) sells fun SEN educational packs to inspire happy learning.

She told us: 'When my eldest son was much younger I designed some resources to help him. I was a nurse with a little teaching experience at the time. His hospital consultant liked them so much that the unit wanted to use them for children with autism, ADHD and communication difficulties'.

Eventually, the kits were licensed to a leading educational company and Vanessa now supplies schools, parents and professionals.

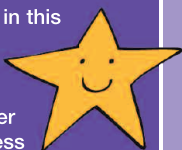
Now we're giving one lucky reader the chance to win a black sensory pop-up tent (size 142cm squared), worth £95!

Not only that, but it will arrive complete with Starpacks' *Calming and Soothing light-up kit* to go inside, worth £59.99! The kit comprises a soft glow colour change egg, fibre optic fountain, knobbly sensory light ball and light-up kaleidoscope.



**Calming
and Soothing
light-up kit**

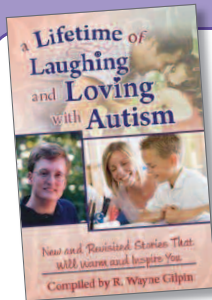
All you have to do is hunt for Starpacks' cute star logo in this issue. Then write to auidsmag@gmail.com telling us where it is, with 'Star' in the subject header and your name and address alongside your answer.



Closing date November 30th 2013. Editors' decision is final. No cash alternative. The winner's name will be published in our January issue.

Good luck!

Reviews



A Lifetime of Laughing and Loving with Autism - New and Revisited Stories That Will Warm and Inspire You

By R. Wayne Gilpin
Published by *Sensory world*
- imprint of *Future Horizons*
£11.50 • ISBN 9781935274643

This is a collection of short stories and anecdotes compiled by the founder of an American publishing company that specialises in autism resources. He is also father of an autistic son.

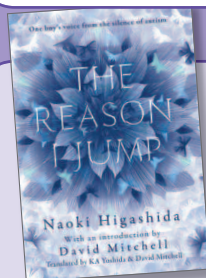
The book in its entirety is a collection of memories from a wide range of parents, plus the occasional professional, covering a variety

of topics. Some of the stories are no more than a few lines long, which makes this book a good coffee table addition.

At times it depends on how cheesy you like your reading, so I recommend adding a good ole pinch of salt here and there, but in other places it promises to make you laugh and cry in equal measure.

This assortment of heart-warming tales will remind you that you are not alone, and that children with autism do say the funniest things. Despite this being one of many similar books on the market, it provides a little light relief among some of the more scary information that may be thrust upon you.

Laura Keeling
Speech and Language Therapist.



The Reason I Jump

By Naoki Higashida,
translated by K. A. Yoshida
and David Mitchell
Published by *Sceptre*
£12.99
ISBN 9781444776751

The Reason I Jump, which has become something of a phenomenon since its publication, is written in the first person by Naoki Higashida, a teenager from Japan with a diagnosis of autism.

The book's introduction states that Naoki's autism made dictation out of the question and computers too distracting. It also says that his autism is severe enough to make spoken language pretty much impossible, even now. Naoki himself reports that 'sometimes I manage a few words - but even these can come out the complete opposite of what I want to say!'.

It's these limitations - and Naoki's young age (he was just 13 when he wrote it) that make it

a truly remarkable achievement and a captivating read. The author used an alphabet grid, pointing to individual letters, to write it.

The book is divided into short chapters that answer popular questions such as 'Why don't you make eye contact when you are talking?' to 'Why do you like spinning?' The book gives a unique insight into one individual's experiences of the sensory world and the daily challenges with which he is faced. Its author offers advice on how to best support individuals with autism through these obstacles and emphasises the importance of people's understanding and patience in giving him hope.

Both beautifully written and engaging, *The Reason I Jump* makes for an easy read, perfect for parents with little extra time to spare. It is important to remember, however, that this is the perspective of one individual and although much of the content may apply to our young people, one size does not fit all.

Hannah Venton-Platz
Assistant Psychologist.



Pronouns with Spingo The Speech and Language Store

For both iPhone and iPad • £1.99

Flushed with the success of Spingo's Language Universe, which earned its makers AuKids' prestigious reader award for Best App, comes their latest launch - Pronouns with Spingo. The Speech and Language Store, (once named Talking Wizard) have created an equally appealing game to help children of all levels understand pronouns. Once again, it is beautifully flexible and the amount of pronouns, and the particular ones you want to practise, can be selected and gradually raised in number. If you select objects and give them to the right people, you earn Spingo's delighted reactions as well as the reward of being able to personalise your virtual bedroom with groovy accessories. This really is a super game that makes education so fun they won't even realise they're learning!

Debbly Elley



WIN

**A FREE SPLINGO
PRONOUNS APP!**

Simply 'Like' The Speech and Language Store on Facebook and post the comment 'AuKids readers love Spingo!' One winner will be selected at random and sent a code to download the app for free. Closing date 30th November 2013.



Labelled With Love



A quick glance at any of the signs on the left tells you a load of information in far less time than it would take to explain it. That's why AuKids is such a visual magazine. We are programmed to respond to visual signals and yet we are socialised to be almost exclusively listeners. Those who find it difficult to process a collection of sounds need better ways of receiving, retaining and relaying information. Here's where we as parents can help our kids, and there's a system that can help us to achieve this - TEACCH.

Division TEACCH started in 1966 as part of the Department of Psychiatry of the School of Medicine at the University of North Carolina in the USA. One of its many aims is to modify a child's environment, giving greater structure and predictability when it comes to common tasks. This enables them to filter out the 'fuzz' and to learn better, using their visual strengths whilst addressing their weaknesses.

The techniques common to TEACCH are minor adaptations that can help our kids to function more happily in the real world and make a big difference to their understanding of their surroundings.

Earlier this year, Tori attended a TEACCH course hosted by the Together Trust in Cheadle, Cheshire. It was presented by Professor Gary Mesibov, former director of Division TEACCH. Some of the ideas suggested to help kids cope with a range of demands could be put to great use at home. These are what she focused on, and here are some of her favourites. Many of the examples given were classroom related, so we've translated the ideas for the home.

OUR KEY:



What you can do



What it helps with

1. STICK WITH IT

- Label drawers and cupboards with photos, pictures and/or written words.
- This increases a child's independence, helps them to make sense of the world and gain control over their environment and can improve their problem solving and communication skills.

2. WHAT NEXT?

- Show them that they can have something 'later' by using a NOW and NEXT card. Use Blu-Tack® to stick a picture of the item under each word when appropriate.
- This turns a difficult abstract concept into a concrete visual and will improve understanding, helping with difficulties that can happen (ie. a wobbler) if a child doesn't understand when they're getting something.

3. ZONED OUT

- Give clues in the home to ease confusion over purpose. Use different colour iPad covers to help a child to grasp whether you are using it for play or education; keep distracting screen games away from sleep areas; make a 'chill out zone' in a corner of a room that is clearly defined for that purpose and have a set place for completing homework, if your child is given some.
- The absence of doubt here will create a more predictable home life which will help to settle and comfort a child. Having such stability, rather than making them more inflexible, will give them enough confidence and security to improve overall flexibility.

4. UNDERCOVER ACT

- Cover up distracting and irrelevant activities/objects. Put a cover over the computer when it's not in use, put toys away after they're finished with.
- A tidy house really does equal a tidy mind when it comes to autism! Problems with executive functioning can mean that staying on task is difficult for an autistic child. Reducing distractions, both at home and school, greatly helps kids to focus.

5. CRACK THE CODE

- Introduce colour coding systems. Their toothbrush, their towel and their flannel, for instance, are all red - can they show independence by finding them when they need to, even if they're in a different place from usual?
- This is a great way of helping a child to increase their flexibility and to problem solve for themselves; something may not always be in the same place, but if it has the correct colour on it, it can be found using initiative.

6. Keep it Together

- For older children, you can also colour code different subjects in school. Cover all science books in green, for instance, plus items needed for science so that they are encouraged to gather all 'green' items needed for that lesson.
- This helps with planning and executive functioning, whilst narrowing down the field of possibles and helping them to focus on what's important.

7. SLOW REVEAL



Limit their focus. For a small child who struggles with a shape sorter, cover up some of the holes. For a child faced with a daunting page of homework, either reveal only one question at a time through masking the others off, or use coloured labels to show when the work starts and when it ends. You can even include stickers to indicate the amount of space for them to write in, so that they understand they aren't expected to write reams!



Clear beginnings and endings can really reduce the panic a child faces when overwhelmed with too much information. Creating structure makes tasks a lot easier and also helps a child to work systematically.

8. RING THE CHANGES



Highlight changes. At school, a timetable change could be highlighted in another colour; at home, this could work on a calendar.



This helps a child to predict the future, making it less stressful, and therefore gives them extra control over their environment.

9. Switch and Swap



Change the nature of a task. Get them used to sorting objects according to shape, then swap the task so they are sorting the same items by colour instead. Think about how you'd explain this visually, by using a little example or a picture. This is generally a good thing for neurotypicals, too! Do something in a different way to work the little grey cells.



This really increases flexibility of thought.

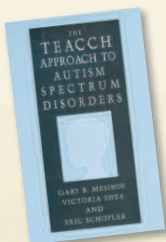
10. The Day in Pictures



Use visual schedules and encourage your child to tick off each activity when it's finished.



This helps to create a more structured and predictable environment that will help your child to understand what's coming next in a really concrete way, increasing security. Great for home and school, particularly when the routine isn't familiar.

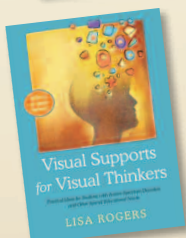


Further Reading

• A complete listing of research papers, assessment tools, publications and video material is available from the TEACCH website: www.teacch.com/publications.html

• **The TEACCH Approach to Autism Spectrum Disorders** (Issues in Clinical Child Psychology) by Gary B. Mesibov, Victoria Shea and Eric Schopler, available from Amazon at £41.35 or on Kindle £31.01

• **Visual Supports for Visual Thinkers** – Practical Ideas for Students with ASD and other special needs by Lisa Rogers published by JKP Paperback £29.99 ISBN 9781849059459



DVD For Autumn Evenings COMPETITION TIME!

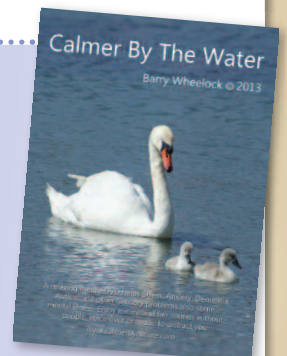
We recently came across *Calmer By Nature's* latest DVD, *Calmer by the Water*. The company creates films of the British countryside without intrusive commentary or music, just natural sounds which allow its audience to escape. *Calmer by the Water* is the third film by Barry Wheelock who, after a period of severe stress in his own life, began to film rare moments in nature. This kindled a passion for wildlife that has enabled him to help others including those with autism, who can use the films as a calming and coping strategy. *Calmer by the Water* is available from www.calmerbynature.com for £16 plus p&p. You can watch a sample clip at www.calmerbynature.com/products.html

WIN IT!

AuKids has copies of *Calmer by the Water* to give away to three lucky winners. Just e-mail us your name and address, with the word 'calm' in the subject header, to aukidsmag@gmail.com, no later than November 30th 2013.

Good Luck!

Our usual terms and conditions apply. Winners' details will be sent directly to Calmer by Nature so that they can send out your prize.



Together for autism

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

- Inscape House School • step-up course at Bridge College •
- community support and short breaks • shared care and full-time residential care.

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



To find out more please contact us
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Ask the Experts

“Some children with autism have rituals that they feel compelled to act upon. These may involve words or actions. Why do they do it and should you worry? We ask our experts...”



* See bottom of feature



Chris Barson
RNMH, GWCMD Dip

Chris is the founder of training company Positive About Autism www.positiveaboutautism.co.uk

Prior to that, he was External Training Manager with the National Autistic Society and still delivers training for the charity. He is a contributing author to *The Autism Spectrum in the 21st Century: Exploring Psychology, Biology and Practice* Jessica Kingsley Press 2010

The future is uncertain. That's for sure! However, if you are a kid with autism that's especially true. Most folk have a kind of inbuilt guidance system that helps us deal with the big "What happens next?" question with a deal of confidence. We can't exactly see into the future, but certain brain functions make us feel like we can.

In kids with ASC, this guidance system is less effective. Hence the future question - what the future might look like and how it will affect me - goes unanswered. And *all* human beings have a problem with unanswered questions. We just can't have that.

The human response to this 'not knowing' goes in several, interchangeable directions. We have options:

- Freak out! We've all done this when we are sent into a tailspin by not knowing what the heck is going on.

- Get real curious about it. Ask questions. Investigate. Test things out e.g. If I do *this* let's just see if that will turn out the way I think it will...
- Distract ourselves. Find something that we recognise and bury our head in it!

You'll be familiar with all of these in yourself, but especially in your young person/s on the spectrum.

So where do the 'rituals' fit in with all this? What sense can we make of them? Well, if the future is unknown territory to you (because of the difficulty you have with *imagining* things) then you could build a bridge to that future made out of stuff that you know and trust.

These would be like stepping stones made out of past events and actions. Trouble is, each time you get to the future, you realise you are still staring into a void you can't handle. So you lay another stepping stone of familiarity and take your next step...

These stones are often what neurotypical folk refer to in people with autism as 'rituals'.

The answer? Well I'd say they are best left alone. Work around them. Make the future less unknown by making it more seeable and concrete. Don't just tell - show. Work on 'staying calm', 'not freaking out' and 'asking for assistance' skills. All these will make the need for rituals a bit smaller.

Of course, human beings are never simple and 'rituals' will have many underlying causes. So play detective and try things. But take it one step at a time.



Dr. Jane Waite and Prof. Chris Oliver

The Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham

Many children with an Autism Spectrum Condition (ASC) engage in ritualistic repetitive behaviours. These

behaviours vary and examples are lining up objects, turning around three times, hand flapping and preferring to do the same activities at the same time of day or place.

There are a number of reasons why these behaviours occur. One reason is that they might regulate anxiety or levels of stimulation by being a predictable and 'safe' activity. In addition, Kate Woodcock, Caroline Richards and Jane Waite from the Cerebra Centre for Neurodevelopmental Disorders at the University of Birmingham, have found evidence that these behaviours might occur because of problems with cognitive processes known as executive functions. Difficulties with executive functions mean that individuals might find it harder to

stop a behaviour once it starts, so it is repeated, or that individuals find it difficult to start something new by generating a different behaviour in response to the same situation.

Ritualistic behaviours should only be reduced if they are having an impact on an individual's well-being or ability to do other activities that are important. When trying to reduce these behaviours, focus on limiting the behaviour rather than stopping it completely. Increasing structure and using visual supports such as timetables, photos and symbols can be effective, as can setting limits to the number of times an individual engages in the behaviour on each occasion. This number can be gradually reduced over time. Some children and adults with ASC might benefit from increasing their self-regulation skills by gaining insight into their rituals and learning strategies to put the brakes on their behaviours. These strategies are more likely to be successful if delivered with support from a Clinical Psychologist who will develop a personalised intervention plan.

Mine has a 'finger clicking ritual' that he does regularly and especially if anxious ... all in a certain pattern.

Amanda Hana Mine, Reader

Bobby has a little speaking ritual, a sort of mantra that he chants to himself whether or not he's stressed. It's like a verbal comfort blanket. Bobby has many other rituals - he sniffs, he coughs, he rolls his eyes. All these appear to be habits which he eventually moves on from, but replaces with something else. One very cute ritual he once had was to line up all his Go-Go characters a measured distance apart in a block formation, about 90 of them. Strangely enough it didn't bother him too much when Alec knocked them over.

Debby Elley, co-editor AuKids magazine



Heather MacKenzie
PhD

Speech and Language Pathologist and Founder of the SPARK* programme (Self Regulation Program of Awareness and Resilience in Kids)

Autism spectrum conditions are described as including restrictive, repetitive and stereotyped behaviour, interests and activities. They may include preoccupation with certain interests, adherence to routines or rituals and repetitive motor mannerisms like finger or hand flapping. These all fall under the definition of 'rituals': they are repetitive, rule-governed and inflexible behaviours.

The use of rituals is, for the most part, an adaptive response. For example, the person begins to feel anxious or distressed so adopts a familiar routine. The familiar routine provides stability and a degree of comfort. Rituals can give the person a sense of certainty, predictability as well as pleasure.

They can also be 'just part of what you usually do' - old habits that no longer have any particular function. Difficulties with inhibitory control and cognitive flexibility, two of the main executive functions, can make it difficult for the person to stop the old habits and start or replace new behaviours.

Something we often forget, however, is that rituals and repetitive behaviour are seen in all people, not just those with ASC. When a ritual interferes significantly with a child's or adult's ability to learn and engage in daily activities, or when it makes them stand out socially, it can be a concern. Both of these issues of interfering with life and social alienation are important.

In this case, a good first step is to look at what function the behaviour may play in the person's life. If it helps to calm and centre them, you'll want to know why they're feeling anxiety or distress. This may prompt you to improve the structure in the person's life and add visual support so they more clearly understand rules, expectations, schedules, etc.

After these are in place, observe what difference they make to the

rituals. If the rituals aren't used less frequently or are used more frequently, something else may be going on. It may be necessary to consult professionals who are knowledgeable in Obsessive-Compulsive Disorder (OCD). A little over one-third of people with ASC show the clinical symptoms of OCD.

The next step for helping with rituals that are not part of OCD is to help the person become aware of the behaviour and understand that they have the ability to control it. For example, say to the child, "Sometimes, I notice that your fingers want to twirl string around and around." The critical thing to notice in the statement is that the 'fingers' are identified as doing the action - it's imperative that we don't say it's the child who's engaging in this ritual because he's the 'command central' that we want to appeal to.

Then we have to indicate why it's important to change that behaviour:

"I know that it helps your brain and body feel calmer but other people might think it's weird and might not want to be your friend." See how they respond. If they still engage in the process, move on to introducing a modification to the time and/or place for the ritual.

Now for the modification step: "You could help your fingers learn when it's okay to twirl the string." When, where and how you proceed depends on the child. I've worked with children where the ritual is important to maintaining a state of calm so you find covert ways of doing it; for example, the string could be in the child's pocket. You might also limit it to home and, ultimately, to their bedroom.

The important part of this step is to engage the child in being the 'commander' of his own body and brain and in deciding when and where he can let loose with his rituals.

These steps take time and a great deal of patience. They need to be introduced to the child matter-of-factly and as something that you and they can work out together.

Our son has a ritual of matching characters to other characters like there is some connection between them all! Likes us to repeat what he says while matching too! He is not very verbal so hard for us to understand, but it always makes him feel better.

Mrs Jude, Reader

Jamie has a bath every single day and has done her whole life. We have never stopped her washing her hair as she always gets it wet anyway... but every day she gets in the bath, has a play and without fail shouts "Can I get my hair wet?" We started saying when she got into the bath "You can get your hair wet," but it's as though she doesn't hear us.

Lorraine Scott Young, Reader



Luke Beardon

BA (Hons) PG Cert (Autism)

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

While not exclusively the case (when it comes to autism it never is, is it?!!) it is very often that the reason behind ritualistic behaviour is directly related to what I call 'global stability' - or, lack of it. Imagine a world of chaos - all the things that most people take for granted all of a sudden can no longer be relied upon. Communication breaks down; other people's behaviour makes no sense; the sensory world is totally different for you compared to those around you; socially you have no idea how to behave; things you say are

misunderstood; you get told off for behaving in ways that seem natural to you; people seem to lie to you all the time...all of these are common experiences for the autistic individual.

So - being perfectly sensible and logical, the autistic person sets up systems to combat a lack of global stability - they start to rely on other things less chaotic, i.e. things that remain the same - or, things in their control.

All of a sudden, the individual can focus their attention on rituals that are comforting and secure, instead of having to engage in chaos and confusion; the wonderful sameness of the patterns decrease the horrible impact that unpredictability and change have on the person; they can engage in isolation without having to involve other people. All of a sudden, life looks a lot better...

In terms of concern - if routines are getting more and more complex, rigid, or the person is increasingly reliant on them, it would suggest that their global stability levels are dangerously low. It is always a good idea to support the individual to have a better understanding of the world around them - and the greater that understanding, the less need the individual will have to develop rituals as coping mechanisms.

As a child I always use to run around the nursery and primary school playground obsessed in a 'Groundhog Day' sort of concept, engrossed in my own world of imagery. I use to always over-repeat phrases to names of superheroes I created constantly, as I often played on my own.

Graeme Croton, founder of Project Aspie

? **Do you have a question for Ask the Experts?**
E-mail us at aukidsmag@gmail.com

*Debby's son Bobby lined up Go-Go characters in front of their 'cinema'.

The views reflected in these columns are the panel's personal opinions and may not be relevant to all children with an autism spectrum condition. Parents should embark on intervention programmes only after following the advice of their child's paediatrician and/or occupational therapist.

My son can't walk down the street without touching every front door. Very time consuming and inconvenient!

Reader



Science Fiction & Fact



The rate of autism appears to be dramatically increasing and now it seems that everywhere you look there is a new 'scientific' remedy. Unless you're a research scientist, making sense of hundreds of autism studies (when you're also emotionally involved in their outcomes) is near impossible.

Alongside the good autism science – the careful accumulation of genetic and other

scientific guide to navigating the swamp of information (and misinformation) in the popular media.

We asked the authors to give us some straight-talk on some of the big questions regarding the science of autism.

evidence-based research - there is a large amount of bad science, based on speculation and anecdote.

Geneticist Dr Neil Walsh and Neuroscientist Dr Elisabeth Hurley recognised this and last year published **The Good and Bad Science of Autism**, a



What do you think is the most common misconception that people have regarding the science of autism?

At the moment it's the assumption that autism can be cured. Because autism is a developmental disorder with a strong genetic component (proven through numerous studies since the 1970s), it has no cure. It is a hugely complex condition and numerous genes have been associated with it, some of which are involved in the development of the nervous system at an early age. So far, the genetic bases of 10-20% of cases of autism have been identified.

thalidomide and valproic acid during pregnancy and if the mother suffers from rubella during pregnancy. There are a number of large scale studies currently underway to look at other environmental risk factors. Some factors that have so far been associated with autism include time of conception, parental age, and whether or not the mother took prenatal vitamins (which may have a beneficial role in reducing the risk of autism).

Research in this area is complicated, however, as it also seems that there is a strong interaction between genes and the environment.

extremely unlikely that a gene therapy for autism will be developed.



Why is autism becoming so common?

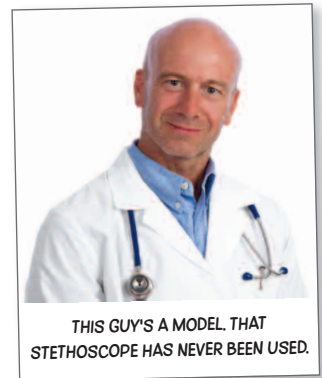
Autism was originally thought to be rare, only occurring in about 4 cases in 10,000 children. Over the last 20 years this estimate has increased and recent studies have reported rates of autism of about 1.1%.

There are two possible explanations. Firstly it could be due to a change in environmental conditions that we don't yet know about, although the vaccination theory has long been discredited. Secondly, it could be mostly or entirely due to the changes in the way that autism is defined and identified, and there is growing evidence that this is the case.

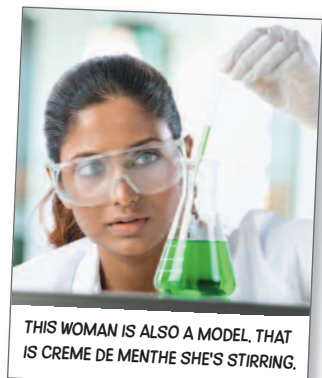
The broadening of the definition of autism to include Asperger's means that there is now a wider collection of symptoms available for diagnosis, including subtler traits not previously considered to be strict signs of autism.

Because of that, some kids who would have been diagnosed in the past as having language disorders and other conditions are now diagnosed with autism. This has been shown through an American study which indicated that the prevalence of other disabilities was decreasing alongside the rise of autism diagnoses.

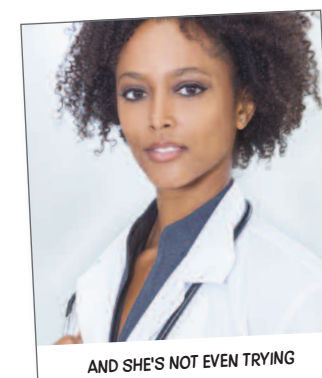
If you look at the prevalence of autism among young and old age groups using exactly the same diagnosis methods, a genuine rise in autism would be reflected in



THIS GUY'S A MODEL. THAT STETHOSCOPE HAS NEVER BEEN USED.



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



AND SHE'S NOT EVEN TRYING



What about the other 80% of autism cases?

In many of these cases, a genetic association with autism has also been established, but the specific genes involved have not yet been identified. New genes associated with autism are being identified on a regular basis. This is an area of research that is still growing and it will likely be many years before we have a full picture of the genetics of autism. Genetics isn't the full story, however.



In principle, could the genetic causes of autism be eliminated with future technology?

The genetic component of autism is very complicated: there are potentially hundreds of genes that have a role in determining autism, but what they contribute and how they interact is not well understood. Medical treatments that manipulate a patient's genetics with the aim of treating a genetic disease (known as 'gene therapy') are at an extremely early stage. The few that do exist only treat conditions with a very simple genetic basis, such as a single gene that is defective, and are associated with major risks. Considering the large number of genes involved in autism, their complex interactions and poorly understood interactions, and the fact that the changes that lead to autism occur at an early developmental stage, it is



What's the current thinking on environmental causes of autism?

Although it is now clear that genetics plays an important role, it is likely that there are also some environmental factors which may contribute to autism. Known environmental factors associated with autism include exposure to

larger numbers of autism in the younger group. In fact a large-scale survey in 2009 by the NHS and the University of Leicester found that the rates were the same when you applied the same diagnosis criteria.

In other words, it is our changing methods of diagnosis that appear to account for much of this rise.

Other factors, like better awareness in the medical community and earlier detections as well as service improvements can account for the increased numbers.



How can I tell which claims are worth looking at?

Good science involves thinking about a possible reason for a problem, predicting what would be observed if that reasoning were to be correct and then testing your predictions through careful experimentation and comparisons.

If your results don't support your proposed reason, it must be discarded or modified and tested again. If they do, then they should be replicated multiple times to be sure, ideally by independent research groups.

.....
The practitioners of pseudoscience can be really resistant to change and are often so convinced that their ideas are correct that no amount of contrary evidence can convince them otherwise.
.....

In order for scientific findings to be published they must pass a strict process of peer-review, where other experts in the field critique and evaluate the results. Once published, studies become available to the broader scientific community, which can then critique them further.

One consequence of the scientific method is that our understanding of the world is continually revised and updated. It means that alternative possible explanations for problems are always considered and evaluated against the available evidence.

In contrast, the practitioners of pseudoscience can be really resistant to change and are often so convinced that their ideas are correct that no amount of contrary evidence can convince them otherwise.



We have read so much about biomedical interventions for autism – what are your thoughts?

We are extremely sceptical of biomedical interventions for autism. Interventions should make sense. You should be able to understand how and why an intervention works. For many biomedical interventions, the reasons why they are claimed to work don't make sense when you think about what we know about autism.

This sets alarms bells ringing for us. It can be very hard for parents to do their own research about interventions, the information out there can be very confusing. Researchautism.net has a comprehensive database of almost all interventions, including biomedical interventions, and can help parents sort through some of the confusing information they receive. *See below right for details.*



Many parents also try special diets. Does the science support any of these?

Currently, the evidence supporting these diets is not very strong. More studies are needed and they need to be repeated in independent groups, and preferably in different countries. Many parents use these diets and have seen a positive effect. Our advice would be

to always work with a professional dietician when making changes to your child's diet. Without professional help, you could accidentally remove something which was helping your child and, although you may see improvements to start with, your child could get worse and you may not be able to identify why. A dietician would ensure that your child's nutritional needs are met.



What tips would you give parents who are thinking about adopting a new intervention for their child?

You should always ask yourself two questions: Is there any research that says it works? Is it safe? Our advice is always to check whether there is research that backs up the intervention. This should be published in a scientific journal, which means it will have been peer-reviewed. You also want to check that there are a few studies which show that it works, published by different groups.

It can be quite hard to get this information. If you are unsure about an intervention, you shouldn't be afraid to ask. Autism West Midlands aims to help people make sense of the various interventions for autism. Other autism charities might also be able to help. Make sure you get independent advice from someone who does not stand to profit from people using the intervention you are considering, to ensure that you get an unbiased opinion.

About the Authors



Geneticist Dr Neil Walsh has studied the genetic basis of evolutionary adaptation using cutting edge molecular biology technologies.

He is currently employed as a Scientific Writer in a medical communications agency, and in his previous academic position at the University of Cambridge he has presented his research at major international molecular biology conferences.



Neuroscientist Dr Elisabeth Hurley has specialised in the effect of light on the development of the body clock. Following her interest in autism, she is now the research officer at Autism West Midlands, contributing to the most recent autism research.



Further Information



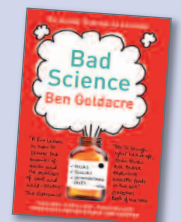
The Good and Bad Science of Autism by Dr Neil Walsh and Dr Elisabeth Hurley is published by Autism West Midlands, price £7, available from shop.autismwestmidlands.org.uk.



We have three copies of the book to give away. Write to us at auidsmag@gmail.com with your name and address, with 'science' in the header.

Winners will be chosen at random after the closing date of November 30th.

.....
Bad Science by Ben Goldacre. Guardian columnist Ben Goldacre's wise and witty bestseller, shortlisted for the Samuel Johnson Prize, lifts the lid on quack doctors, flaky statistics, scaremongering journalists and evil pharmaceutical corporations. The Sunday Times Top Ten bestseller. Published by Harper Perennial and available from Amazon at £6.74 (price at going to publishing).



.....
Researchautism.net sifts good science from the bad. For each intervention, it has a rating telling you how much research backs it up. It also tells you whether there is any risk to health.

GOOD SCIENTISTS...
don't start with a theory and try to prove it; they start with a theory and try to disprove it. To prove or disprove a theory 100% is impossible. A good theory is simply one that has been questioned rigorously and yet the balance of evidence still supports it. In bad science, researchers start with an idea and then look for evidence to support it. Whether their idea is correct or not, they will find a way to justify it.

THE SAFETY NET

The internet can be a fabulous place for kids with autism, giving them an opportunity to socialise in a non-intimidating environment. It can also be a dangerous place; autistic kids tend to be visual thinkers and often love technology, but their autism causes them to be even more vulnerable online than other kids. Put it together and you have a strong case for being extra-vigilant.

Fayaz Malik is a CEOP (Child Exploitation and Online Protection Centre) Ambassador based at Moorside Primary School in Tameside.



Fayaz Malik

He agrees that the Internet can be a fantastic place for autistic kids for a number of reasons: "Young people with autism and other communication disorders often find Internet communication easier than face to face communication. On the Internet, people's use of consistent and easily recognisable emoticons replaces the need to decode people's body language, facial expressions and vocal tone that can be problematic in personal communications."

That's not to say it should replace real life communication, of course, and the need to practise 'real' social skills. But imagine how great it must be for them to be able to relax in a social setting when ordinarily it can be such a strain. There are educational benefits, too, according to Fayaz:

"Internet-learning provides opportunities for learning through repetition that supports children who take longer to learn new things and embeds the learning they do in the classroom by undertaking activities as many times as

they need to, in order to consolidate their learning."

The visual aspect of learning is really important for autistic children, who tend to process images easier than spoken communication.

But...we all know the risks, which can be considerably increased for a child with autism. "The risks for all children can be more profound for young people with a learning disability as a result of increased vulnerability, tendencies towards obsessive compulsive behaviour and social naivety. Pupils with Special Educational Needs are 16% more likely to be persistently cyber bullied over a prolonged period of time."

That's a good reason to get in there early, then. Here's how:

1. MAKING YOUR HOME INTERNET SAFE

Tips from CEOP:



• Install Internet filters

Internet filters are software which are designed to control what content a user can see. It is used to restrict material delivered over the web. For advice, go to Get Netwise at www.kids.getnetwise.org/tools/ which supports parents in choosing tools to filter content. It also identifies child friendly web browsers and software that can contribute to keeping children safe.

• Install child-friendly browsers

Child-friendly browsers automatically filter results that are adult in content and protect against viruses. Anti-virus software should be installed. Get Netwise can help and Fayaz recommends KidSurf – Internet browser software designed especially for children of 3-8 years old. It's a free download and only allows children to access sites online that have been pre-approved.

• Protection against viruses

Microsoft provides excellent free antivirus software at windows.microsoft.com/mse

• Install parental guidance locks on popular sites

Websites designed for a range of age groups that contain adult or disturbing content should have a capacity for blocking certain content using a pin code. Normally this capacity can be found by entering the help/guidance/support/safety centre pages from the home page.

2. KEEPING AUTISTIC KIDS IN THE KNOW



• Child Net International (www.childnet.com) is a not for profit organisation working with others to make the internet a safe place for children. Its Know-IT-All section is fantastic and includes a 'SMART rules' video for kids to watch

- The BBC's brilliant interactive Dongle cartoon is available under the site's activity centre.
- The site has an SEN section for parents and teachers, showing Internet safety rules in BSL and Widgit symbols: www.childnet.com/resources/know-it-all-for-teachers-sen
- Use the following Social Story™, written by SEN Assist, to help your child understand what a password is for. Fill in the gaps with your child's details to make it more meaningful.



About Using A Password on the Computer

I like using the computer. Sometimes I play games like

When I play games, I use a made up name like

I do not give any information about myself like the name of my school or address. People do not need to know about me to play games. I do not need to know about the people I am playing the games with either.

If I am playing a game and I get asked for information about myself I should tell a grown up I trust.

I might have a password to log in to a game and I must keep passwords secret.

A password is a bit like the code that can be used to open a safe. The password stops other people using my account and getting details about me. I must not tell anyone the password except my parents or people who I know are there to help me like a carer or teacher.

If I'm not sure I can always ask a grown up I trust. I want to be safe and I like going on the computer. I know it is important to keep my information secret and safe when I am playing games like

or using the Internet.

3. KNOWING WHAT YOUR CHILD'S DOING



- Listen when your child talks about computer trends.
- Ask other parents what they think of a game before installing it; better that they don't get into it to start with than get addicted and then face a crackdown!
- Keep the computer in a family area with the screen pointing towards the room.
- Every so often, sit and play with your child on each computer game they use so that you're aware of the type of interactions they're having.
- Listen to your child if they tend to repeat what they've heard verbatim; be alert for the clues that something inappropriate may have been picked up from a game.
- Adopt a blame free tone when asking them where they heard something.

4. STAYING SAFE



Tips for managing computer time compiled in collaboration with SEN Assist:

- 1) Try to create a cut-off time for technology in the evening so that your child has at least a half hour period of quiet reading before bedtime and isn't over-stimulated when it's time to go to sleep.
- 2) Create a colourful 'computer' timetable for the week showing the times that they are allowed to be online every day. This visual reminder will help them to recognise and expect that they have a daily limit.
- 3) Try to avoid the discovery of 'YouTube' or games sites with never ending links. Choose ones with a clear end so the child can prepare.
- 4) Make an agreement before the child goes on the computer about how long they will have and giving them a visual reminder of this.
- 5) Use a timer such as Special Direct's audible Time Timer (www.specialdirect.com). Not

cheap at about £30, but worth its weight in gold as a visual tool to show a child how much computer time they have left.



- 6) Do not switch the computer off as the timer goes. This would be unfair and guarantees a bad reaction. Wait till the next convenient breaking point – if you respect your child's need to finish off what they're doing they'll be a lot more respectful of your boundaries.

5. RECOGNISING TOO MUCH!



Rather than dictating, it's better to help kids to recognise their own body's signs that they've had too much time on screens. Here's a list that Debby compiled with her son Bobby and keeps handy when it's time for a reminder.

Although I love my games, I need to stop now because...

- I notice after an hour that my brain becomes so fixed that I can't think of anything else, which means my brain needs a 'break'
- Too much screen time can make my eyes tired
- My brain can become too 'busy' with thoughts of the game, not leaving room for anything else
- Brains need time to recharge just like computer consoles do
- Brains need a healthy balanced diet just like bodies do – time to play on the computer, time to solve problems and time to sleep. Brains also like fresh air!
- I start to feel a little crazy if I have too much screens, my head goes hot
- I can forget that there are other things I really like to do, until I do them

FURTHER INFORMATION

Fayaz Malik is available to give free internet safety training sessions and advice for groups of parents. You may need to cover his travel charges. Contact him at f.malik@moorside.tameside.sch.uk

Fayaz wrote an excellent document with detail on everything you need to know about techno safety, including help with cyber bullying, restrictions for TV and mobile internet safety. It also has a great section for SEN and autism adaptations and tools. The PDF is now available to download at www.aukids.co.uk

SEN Assist creates award-winning CD-ROM games: www.senassist.com

Thinkuknow www.thinkyouknow.co.uk by CEOP has a sing-along safety video and a wide variety of activities and resources.

Super Club Plus www.scplus.com/d/who-are-we is a paid for, safe, children's networking site.

Safe Surfing with Doug www.disney.co.uk/DisneyOnline/Safesurfing is aimed at helping young children understand how to stay safe online featuring characters from Disney's cartoon Doug.

Woogi World www.woogiworld.com allows primary aged children to play games, learn about basic Internet principles and chat safely.

That's Not Cool www.thatstnotcool.com gives the tools to help young people think about what is, or is not, okay in their digital relationships. Aimed at young people 11+.



Trackyour.co.uk

Monitoring Solutions to Assist Parents & Carers of Children with Autism or other Related Conditions

Specialising In
 GPS Trackers
 Radio Monitors
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Locate Where They Are Wherever You Are

www.Trackyour.co.uk
'Providing Peace of Mind for Those Who Care'

NO CONTRACT FEES!



The Last Word

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

Nice Toy, Shame About the Age Range

My twins were five when we started AuKids. Now they're nine, so the nature of my contribution to these columns is changing. I've started to look back on your behalf and think about the things that bothered me which were - in hindsight - self-generated tortures.

On the run up to Christmas, it was age appropriate toys. When Alec was about six, I'd march through toy stores, trying to ignore the flashing, musical, tantalising world of the under-twos aisle. Despite an inner voice telling me that Alec would love it all, the toy packaging blared 18+ months and showed a toddler merrily doing everything correctly on the front. To choose one of these toys would feel like admitting defeat.

If I succumbed to temptation, it was a painful reminder that Alec was, in play terms, still a baby. Reading the box, my heart plummeted and landed with a soggy 'oomph' next to the woman with a baby buggy who had picked up the same toy. I just didn't want the indignity of buying it, for me or for Alec.

There's nothing wrong with what I did next, choosing toys that Alec would like that were age appropriate and 'cool'. His toy garage (largely ignored) was replaced with Hot Wheels - same principle. The light-up piano was swapped with a trendy keyboard and the ball popper game replaced with a marble run.

But what was I really worried about? Just because in neuro-typical terms



TOP OF THE POPS:
Alec used to love this - why care about the baby on the box?

the toy is for a two year-old, this doesn't mean that your child has a mental age of two. In ordinary children, sensory exploration is a stage of development. In kids with autism, sensory input is a way of balancing their nervous system; nothing to do with age, simply what their brain requires.

Alec's taste in TV programmes has matured with age, but he still loves sensory toys and he always will do. I shouldn't have taken it so personally.

There is a danger when letting our pride get in the way of our gut decision-making. If we don't allow our kids to develop at their own pace using the toys they are drawn to, they are never going to be able to fill in the gaps that they may have missed.

The fact is, age guidelines on 'normal' toys are irrelevant to kids with special needs. So just ask yourself three questions: what's the fun value, what's the educational value and will it aid their development? If it ticks all your child's boxes, then quite frankly who cares what it says on the front?

P.S. For great tips on preparing for Christmas, look up Issues 2 and 13 on our archive at www.aukids.co.uk (username and password required).

★ Cover Star ★

WILLIAM SHEPPARD

William's mum Sue says: William was diagnosed with autism at about 3 1/2 and he's now 5. Mainstream did not work for his reception year so he has moved to a unit within a mainstream school, he is very happy there. William loves trampolining, swimming, play centres, riding bikes and playgrounds.

He is obsessed with emergency vehicles, cars, Eddie Stobart trucks, and buses and trains...he recognises all the car logos and a lot of models. His favourites are VW and Audi...he is not impressed that we drive Toyotas!

At home he 'constructs' all of the above using toys, furniture and soft furnishings and loves to dress up as an Eddie Stobart driver, or a fireman whilst doing it! He makes the most incredible siren and truck noises and has even fooled a female fire fighter at an open day! He is a real chatterbox, a charmer, and has a wicked sense of humour. He wins over everyone who meets him!



Think green! Recycle AuKids www.aukids.co.uk

Celebrity SPOTLIGHT

HUGH MARTIN

*He flaps his hands and stamps his feet and spins around both ways
He'll crash and smash his way through things
My furniture's seen better days*

*He'll bite and scratch to reach his goal and war wounds I have plenty
But when he's out, even for a short while
The house is eerily empty*

*He likes his frisbees, balls and swing
In particular in The Night Garden
He'll chase me round and round and round -
I wish I could have a warden*

*Days can be hard and often a battle
The nights can be difficult too
But this is part of every day
With our little Hugh*

*He's a joy, he's a treasure - he's also full of fun
He needs 24/7, but gives lots of pleasure
He's my little lad, my autistic son.*

by AuKids reader Julie Martin

Cygnet Health Care

Autism and Asperger's Syndrome Services

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

OUTREACH SUPPORT:
For individuals aged 5-64.

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

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

CYGNET'S OTHER AUTISM SERVICES INCLUDE:

- Springside South West, Exeter:** Outreach support services.
- The Springs Community, Kent:** Residential care for individuals aged 16-64.
- The Springs Unit, Harrow:** Secure inpatient care for adult males with autism & Asperger's.

For more information on any of our services please visit www.cygnethealth.co.uk or call Cygnet Central: 0845 070 4170

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