



Issue 27
Spring 2015

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Positive Parenting for Children with Autism Spectrum Conditions



The Autism Codebreaker
Phoebe Caldwell
on engaging the
hard to reach child



It's A Sensation!
Olga Bogdashina's
new column on the
sensory world



Naughty or Nice?
Changing your autism
parenting style for
great results



National **Diversity** Awards
NOMINEE

PLUS

WIN therapy furniture from the Blossom for Children range, **colour changing bubble lamps** from Valuelights...

AND MORE!



Letter from the Editors

Debby
Tori



Welcome to our spring issue!



ROBERT AND ROBOT: Debby's son Bobby befriends humanoid robot NAO, used for interaction therapy, at last year's Autism Show

March and we have an interview with her inside this issue.

Also in March, we trained children's shoe-fitting staff at John Lewis Cheadle in autism awareness. Well done John Lewis for launching this autism-friendly initiative, which we hope with our help will go from strength to strength and even in time be rolled out to other stores across the country.

A quick heads up that we've been nominated for a National Diversity Award under the category of Community Organisation - Disability. If you'd like to vote for us, have a look at the advert below. Nominations close on June 21st.

Enjoy the magazine!

Tori & Debby

P.S. For our July issue we're collecting your best recommendations for places to visit this summer. Have you been impressed with somewhere in the UK? Does it have an inclusive, flexible and friendly atmosphere?

Put 'Recommend' in the subject header and send your comments no later than June 15th to aukidsmag@gmail.com - photographs to accompany them would be welcome.

COMPETITION WINNERS FROM ISSUE 26

Carolyn Neal, Widnes; Elaine Clarke, Liverpool; Tina Quinney, High Peak; Judith Woolven, Lancaster; Paula Greco, Uruguay; Amanda Ayres, Weaverham; Paula McClinton, Lisburn; Elaine Jones, Cheshire; Natalie Barnes, Hull; Max Yorke, Stockport; Delia Barton, Lewisham; Andrew Graham, Wigan

If you've picked up a copy of AuKids at the Autism Show, thanks for joining us! We are delighted to be a media partner this year. We hope you like what you see and if you do, don't forget to subscribe online at our website www.aukids.co.uk All subscribers have free access to our AuKids archives, so you haven't missed at thing!

By the time we go to print, fingers crossed our new-look website will be up and running! Notable changes include much easier navigation of our past issues, so that you can flick through articles of interest to you whenever you fancy it. It also features our new events system AuKids Live! You'll be able to see details of forthcoming talks by the AuKids team and book yourself onto our events.

The magazine team have seen a lot of fantastic speakers over the years, with AuKids Live! we'll be able to invite our readers to listen to the ones we liked the most. We started off with a workshop with Phoebe Caldwell in

National Diversity Awards 2015
Celebrating Unity in Society

Nominate Us! For the Community Organisation Award
nominate.nationaldiversityawards.co.uk

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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Link to the best help and support

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



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READERS' PAGE

Send your letters and images to [auidsmag@gmail.com](mailto:aukidsmag@gmail.com)

Celebrity SPOTLIGHT

Name: Aimee Wells **Lives:** Manchester
Age: 11 **Diagnosis:** Autism

Q: How do you feel about your autism?
A: I like it, I don't think about it.

Q: What does it make you good at?
A: Being creative — I have a vivid imagination and write good poems.

Q: What do you struggle with?
A: Maths

Q: What do you like?
A: Biting things! I love Pokemon and animals, especially cats, I know most breeds of cats. I like swimming and want to do competitive swimming.

Q: What do you dislike?
A: Maths, loud noises and I hate Justin Beiber and One Direction.

I have a vivid imagination and write good poems



Aimee

Q: What do you think of Aukids magazine?
A: Good but it needs a kids' section.

AuKids replies: Hi Aimee thanks for your spotlight! There are so many different things that kids like that it's really difficult to include a kids' section that keeps everyone happy. The best magazine we know that's aimed for kids on the spectrum is *The Social Times*, published in America by AAPC Publishing - www.aapcpublishing.net We hope our kids enjoy searching for characters we hide in the magazine and we will certainly publish reviews or letters sent in by children that are helpful for the parents who read AuKids.

CO-EDITORS.



LEGGING IT: Brendan is on a mission to build a secondary school in Malawi

Brendan Takes a Challenge – and Runs with It!

MOST of us are happy to do a sponsored walk in aid of charity. AuKids reader Brendan Rendall, (who also works as a support worker for our sister company Time Specialist Support, working with autistic youngsters), has gone just a bit further.

He is running THREE marathons in consecutive months to try and raise a massive £35,000. He aims to use the money to help build a secondary school for orphans in Malawi.

He tells us: "Since 2008 I have been a supporter of Friends of Mulanje Orphans (FOMO), an incredible charity that feeds, supports and cares for 5,000 orphans. Having seen the development of their skills centre, care centres, hospital and clinic, I've found the work they have done truly inspiring. It's a charity run by volunteers and therefore the money gets to where it is needed."

Between 2008 and 2009, Brendan cycled across Malawi visiting a range of projects – including orphanages, HIV clinics and farming resource centres. He says: "Seeing poverty of that level first hand was extremely emotional and completely eye opening. Everyone is moved by scenes of poverty across the world on the TV, but you switch it off and then are desensitised to it, but seeing it first hand, it stays with you.

"Yet behind the poverty is an incredible spirit, a pure happiness from the children that I have never seen before. It has given me such an appreciation for life."

This year, Brendan will be completing three new challenges to raise money for the art and science blocks of a new secondary school for orphans there. Having just completed the first phase of his challenge by running the Manchester Marathon on 19th April, he now sets his sights on the Windermere Marathon on 17th May followed by the Lakeland Ultramarathon on 27th June.

"I have set myself a huge challenge," he agreed. "But I am determined to achieve it. The Lakeland Ultramarathon is going to be extremely tough - 35 miles through the Lake District up steep mountains, trails and valleys.

But the vision of opening this art and science block will inspire me to succeed.

"I would love AuKids readers to get behind me, helping these orphans receive an education, hope and a life out of poverty."

You can follow Brendan's progress on twitter @helpfomo35 and donate by visiting www.justgiving.com/helpfomo35 or texting FOMO99 £1- £10 to 70070.

Cover Star

Dexter Wells

Age: 4 **Diagnosis:** Autism

Dexter loves building Lego®, reading books (especially rhyming ones), singing and dancing to music and dashing about in the park or a soft play centre. He's an affectionate and happy child who likes eating Italian!



Dear Debby and Tori,

HELLO FROM SUNNY MONTEVIDEO!

I was delighted to meet you both at the NAS Conference in Reading last November. As a professional working with autistic children, your talk made me reflect on the importance of continuing to work towards changing the way autism is understood here at home in Uruguay and on the need to listen, trust and empower parents, as they are our most valuable partners.

Unfortunately, in Uruguay autism is still seen as a tragedy, a disability rather than a difference, a problem that has to be solved, a mistake that has to be amended. This vision is shared by the wider population, but also by many professionals and even parents who struggle to find positive things to share about their children. Even though I lived and worked in the UK for nearly a decade, where things are very different, it's difficult not to become negative and pessimistic here at home. It's all doom and gloom when it comes to autism! (No "cheerful South American" stereotype I'm afraid!)

After 2 years of being back home, I went back to England last November to visit friends and do some professional training. I came back home inspired and determined to continue to work on changing the way most Uruguayans see autism. This year, I will open a Centre for Children with Autism in Montevideo. I hope it will be a place where autistic children can learn, enjoy themselves and have fun. But more importantly, I hope it will be a place that shows non-autistic people how brilliant autistic children are and how much they have to offer.

Paula Greco.



Reviews and Prizes



Time for Some Rock 'n' Roll!

Blossom for Children (www.blossomforchildren.co.uk) is a social enterprise selling fun therapeutic furniture for kids with special needs. Every spare penny goes straight back to its parent charity, Tree of Hope (www.treeofhope.org.uk), where they are passionate about improving the health and lives of sick and disabled children. Tree of Hope supports families and helps fund surgery, treatment, therapy and equipment in order to free children from suffering, giving a better quality to their young lives.

Text TREE01 £10 to 70070 to donate and make a difference today.



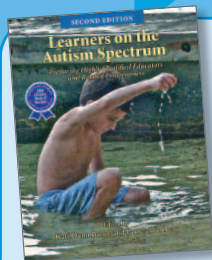
The bObles Elephant is one of our favourite bits of kit! It's the big rocker of the bObles therapy furniture range, one of seven stylish pieces designed to help develop gross motor skills, build core strength, develop muscles, strengthen bones and make home therapy great fun.

The bObles elephant comes in purple, jade, blue or pink and usually retails at £99.99, but you can win him with AuKids! **Just find this blossom tree logo hidden somewhere in the magazine.**



Send your answer to aukidsmag@gmail.com no later than May 31st 2015, with 'Elephant' in the subject header. If you prefer 'snail mail', send a postcard to us at AuKids, PO Box 259, Cheadle, Cheshire SK3 9BE.

One winner will be chosen at random from entries received before the closing date. No cash alternative.



Learners on the Autism Spectrum: Preparing Highly Qualified Educators and Related Practitioners

Edited by Kari Dunn Buron and Pamela Wolfberg
ISBN 9781937473945

Second edition, Published by AAPC Publishing, £60.31 – 15% discount and free postage when you order it from www.eurospanbookstore.com

When I first received this book to review my instant reaction was that it looked a bit too mammoth for the average parent who wants quick info. Hardback, giant, heavy, just over 450 pages long, this second edition text book is in fact a brilliant reference on autism that will ensure you have some leading professionals at your disposal, ready to give you some excellent information. If you're a professional reading this, I'd stay ahead of the game and get it!

Over the course of 17 clearly crafted chapters written by a collection of big names in the field (including Gary Mesibov, Simon Baron-Cohen and Brenda Smith Myles to name but a few), this tackles everything from the neurology of autism to interventions, communication, sensory processing and play. It's bang up to date with the research that it quotes and it provides the reader with a great filter through which they can make sense of current thinking and practice

relating to autism.

Think of this book not as a bedside read but more as a four-day conference without the travel, parking and sandwiches. When you look at it that way, the price tag isn't really that bad.

This will be well-thumbed by university students and I love Carol Gray's foreword, in which she reminisces about selling her old text books as a sort of end-of-course ritual. 'As you gather up your books at the end of term, you may consider selling this book along with the rest. I wouldn't do that if I were you.' Tori and I will certainly be dipping into this in future.

Prize Time!
We have a copy of *Learners on the Autism Spectrum* to give away. Simply answer this question:
Q How many chapters does the second edition of *Learners on the Autism Spectrum* have?
Send your answer to aukidsmag@gmail.com no later than May 31st 2015, quoting 'Learners' in the subject header. The winner will be chosen at random from entries received before the closing date and the winner's address will be forwarded to Eurospan so that their prize can be sent directly.



Autism As Context Blindness

By Peter Vermeulen
Published by AAPC
£18.95
ISBN 9781937473006

It's taken me a while to get around to reading Peter Vermeulen's much feted book *Autism as Context Blindness*, because it's a fairly sizeable read and not something that your average parent is going to pick up before bedtime.

That said, I'm glad I did because it's a very important book, even a 'game changer' as Brenda Smith Myles points out in her preface. It's so easy to reduce autism to a set of typical characteristics. Actually autism is a whole-brain condition and many of the difficulties experienced are the result of different parts of the brain not co-operating with each other on a very subtle level.

If we take any element of our understanding – the way we comprehend words, the way we hear them and the way we interpret feelings and behaviour in others, context plays a vital role. Neurotypical brains adapt and react quickly to a context, whereas someone with autism might focus on the correct thing, but miss its context (and therefore meaning) entirely.

Throughout this book - a must for anyone fascinated by the psychology of autism -

Peter Vermeulen painstakingly explains the confusion this can cause, illustrating it with many examples of current research as well as lively anecdotes and images to illuminate his points.

My favourite is the image of a 'salt shaker' surrounded by coffee cups and a cafetiere. A student apparently passed this scene and asked his coach 'Why do you give people salt?' It did look like a salt shaker, but someone without autism would assume by its context that it couldn't be salt but sugar. The autistic student didn't have sufficient flexibility of thought to adapt his view according to the context.

The book gives a whistle-stop tour of how the brain works to interpret context before covering context in perception, in social interaction, in communication and in knowledge. Can context sensitivity be learned? Essentially, no, because it happens at a sub-conscious level, context varies so much and context sensitivity is spontaneous.

We can however, teach autistic people a compensation strategy for the lack of it – and this book points briefly to how this can be done. Says Vermeulen: "You cannot teach a blind man to read a book like everyone else does, but you can teach him Braille so that he can, by a detour, read with his fingers". It means pointing out context and being far more concrete in our own communication.

Debby Elley,
Co-editor



Understanding Stanley: Looking Through Autism

By Rosie Barnes
Published by Lampshade Books
£15.00 • ISBN 9780992952105

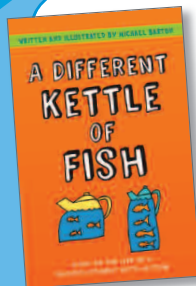
This book aims to give the reader an insight into what it might feel like to be autistic. It is aimed at anyone who hasn't already read much about autism - those who will mostly never find the time or inclination to sit down and read a text book on the subject. Compiled by a professional documentary photographer (and mother of a child with autism), it is a collection of photographs and quotes that follows her son's

journey from being a young boy through to early adulthood. This format makes it very easy to read, and also provides a different perspective that text alone can never achieve.

After an excellent four page introduction by the author, the rest of the quotes come from a range of people on the autism spectrum or professionals working in this field. They wonderfully complement the beautiful images throughout, and together make for a unique, revelatory and at times moving experience for the reader.

The book finishes with two pages of "Can you imagine this?" scenarios, again designed to try and let you see the world as someone on the autism spectrum does. I don't mind admitting this brought a lump to my throat!

Mark Haworth,
AuKids reader panel



Different Kettle of Fish: A Day in the Life of a Physics Student with Autism

Written and illustrated by Michael Barton
Published by Jessica Kingsley
£9.99 • ISBN 9781849055321

Since I was a child, I have always thought in pictures. This book follows Michael's journey as an adult with Asperger's as he travels from home to university - and what he encounters during the day along the way. It's funny - all the things he pictures in his brain when someone uses an idiom. For me, it's nice to know that I'm not alone - I think the



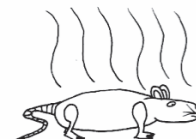
PEOPLE ON THE SAME WAVELENGTH

same when people say strange things. It shows how people should think before they speak to an autistic person.

The author is a highly intelligent man with Asperger's whose previous book *It's Raining Cats and Dogs*, (which explained in cartoons the meanings of every day idioms), was very successful.



HE HAD EGG ON HIS FACE



TO SMELL A RAT

The book is in a similar format to his last one, but more of a story. I think a child with autism who can read for themselves would find it funny. It would also be ideal for parents, as it gets across what we really mean by thinking in pictures.

Tim Tuff,
adult with autism

Get a Sensory Room for under £50!



Tornado Colour Changing LED Novelty Bubble Lamp

We all know that if you want fibre optic spaghetti, twinkly carpet and a massive bubble tube, you're looking at spending thousands of pounds.

But if you're a bit savvy, there's plenty of really effective things you can add to a bedroom without spending a fortune or using up all the play space.

Anyone who follows us on Facebook will know that we already have a thing about LED colour rotating light bulbs. You just screw them into a normal light fitting and voila, instant moving disco lights bobbing round the bedroom. You can buy them from under a tenner from Ebay sellers but make sure they are UK-based so that they are CE approved.

For that other vital sensory room centrepiece, try Valuelights (www.valuelights.co.uk). It sells superb creative LED Mood Lighting for fabulous prices. Keen to give their products a shot, we asked for a Remote Controlled Colour Changing

Bubble Lamp with Multi-coloured Balls to try out, which sell at £24.99.

It's got to be pathetic at that price right? Wrong! First thing you have to do is to fill it up (with distilled water to prevent it from going mouldy). We cooled about 4 kettles of boiled water and that did the trick.

Then put the lid on, switch on and you're good to go.

It's not as fat or as tall as the ones you get when you add another zero to the price, but it's still a pretty impressive size at 90cm.

These are not designed with SEN kids in mind, so our first question was how much force it would withstand. After running some tests, Valuelights advised that the acrylic (PMMA) tube can take 1.7Kg impact on a square mm. Pretty solid - and it feels it too, although it's acrylic you can only tell by the warmth to the touch that it isn't glass.



Aquarium Bubble Fish Table Lamp

There are a few considerations to take into account for children with autism. Firstly, the dinky little remote control is very easy to use, but the buttons are small and so not great for kids with fine motor difficulties. We fed this back to them, so you may get a better option in the future.

Also, the lid fits loosely so that you can fill it with water. It's advisable to secure the edges of the lid with Sellotape.

Finally, all the bubble lamps use an air pump so they make a low buzzing noise. Debby's son actually liked this and put his ear right up to it - you can't always tell how they'll react - but worth knowing. The Tornado Vortex Colour Changing LED Bubble Table Lamp is quieter, though. Please note the remote control only comes with the tall floating balls model, the fish one changes colour on its own.

That said, these images don't begin to do justice to how gorgeous this thing looks when it's on. It really does look sensational, with lots of great colour combinations and the soothing motion of endless bubbles. This is really calming for autistic kids and just as relaxing for their parents! We couldn't take our eyes off it.

WIN ONE!

The folks at Valuelights want more autistic kids to enjoy their products, so we have some great prizes up for grabs!

TWO lucky readers will win a colour changing bubble lamp with multi coloured balls, worth £24.99.

TWO runners up will get a choice of either an Aquarium Bubble Fish Table Lamp worth £14.99 or a Tornado Colour Changing LED Novelty Bubble Lamp also worth £14.99 as their prize.

Just answer this simple question. Which of the following products do Valuelights NOT sell
a) Ceiling lights
b) Floor lamps
c) Outdoor lights
or d) Car lights?

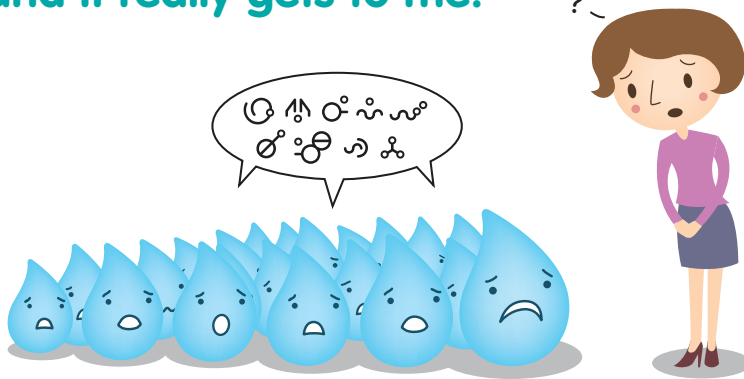
Send your answer to auidsmag@gmail.com no later than May 31st 2015, quoting 'Lights' in the subject header. Winners' details will be sent directly to Valuelights so that they can send you your prize.

valuelights





“How do I know what’s upsetting my child? I can’t always interpret his tears and it really gets to me.”



Luke Beardon

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

Not the easiest question without being there to observe, and of course all children will differ - however, there are some areas that you might want to think about that may not apply to the predominant neurotype (PNT) child. These include:

- Communication /misunderstandings
- Sensory discomfort
- Rumination over baffling events
- Worrying about future events
- Concern (perceived, fact, or fiction)
- Feeling poorly

Communication - Often a child will have heard something (not always even intended for their ears) that subsequently does not compute. Two ways of reducing this are to ensure they know when communication is meant for them (e.g. by using their name) to reduce ambiguous

language (e.g. “We’ll do that in a bit”). Avoid language that, when taken literally, could be misunderstood (e.g. “We’ll do that in a minute”). So, change to “We’ll do that at 6pm,” (make sure you then do it at 6pm) or “We’ll do that after tea”.

Sensory discomfort -

The world is crammed with a plethora of sensory experiences, many of which will be perceived very differently by the autistic child compared to their PNT peer. Always be on the alert for anything that might cause sensory distress, and make use of all the wonderful gadgets now available to reduce unwanted sensory incidents.

Rumination - Often, children with autism will experience events that they simply cannot make any sense of; alternatively, they might be replaying a past event thinking about it from every angle to ascertain what might have gone wrong and why. It can be helpful to have some kind of process whereby thoughts can be ‘ended’ - for example, by drawing a picture representing the troublesome thought and (safely) burning it.

Worry about future events - Lots of autistic children fear the unknown. Often, it is helpful to have as much information about future events as possible (this is irrespective of whether the planned event is a positive

one such as holiday, or negative such as going to the dentist). Visuals can be of some comfort - Internet sites showing the holiday venue, photos of the dentist’s waiting room, and so on. It may even be possible to video in advance, to give the child a better picture (literally) of what to expect. Of course, written planning and schedules may also be of benefit.

Concern - Sometimes it is astounding what children worry about. It may be that they think Dad is upset with them (when in fact he was simply frowning at the smelly cat), or dreadfully concerned about a character in a film or book. I like ‘problem books’ where the child can write or draw things that concern them in their own time and space. It is amazing how much information a parent can get from a child in this way!

Feeling poorly - It may be that your child does not have the understanding that when they are in pain something can be done about it. Sometimes children simply do not realise that unless they indicate that they feel unwell then it is not necessarily clear to a parent. Having things like diagrams of the body (to show where) or a pain chart (for severity) so the child can indicate where they feel unwell and how much pain they are in can be a great way to share effective communication.



Heather MacKenzie

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

Crying is a natural emotional response to certain feelings. It can be related to discomfort, sadness, anger, frustration, stress, confusion, worry, disappointment, anxiety, fatigue or hunger. Children may also cry when they’re overwhelmed or overstimulated.

Here are some steps to follow:

1. **Stay calm.** Your emotional state can increase your child’s stress and anxiety and compound issues. We know that most children on the spectrum are ‘emotional sponges’ who absorb feelings around them, regardless of whether they’re directed to them or not.
2. **Try to comfort him.** Whether a hug, soothing words, calming song, quiet small space, weighted vest, etc. Don’t talk a lot - that can add to any stress your child is feeling.
3. **Check to make sure there are no physical causes:**
 - a. Has your child eaten something nutritious within the past two hours?
 - b. Did he sleep well last night? Tired children can be inconsolable. It might be best to find him a quiet spot with a favourite book, video, music so he can rest.
 - c. Does he have a fever or any other signs of illness or pain (constipation, bumps, bruises)?
 - d. Is there some smell, sensation (e.g. itchy shirt tag, wet clothing), taste or sound that is causing agitation?
4. If you can’t find physical reasons, **look for possible cognitive and social causes.** What was he doing immediately before he started to cry? Did something happen earlier that’s causing him distress? You might ask his teacher, therapist, sibling, etc.
5. **Ask him to show or tell you what happened.**
6. **Be okay with not knowing the real reason for his tears.** There are some things you’ll never know. Just be confident that you comforted him as well as you could and you tried your best to find out why he was crying.



Olga Bogdashina

Olga Bogdashina is Honorary Professor, Programme Leader, Chief Research Fellow and Lecturer at the International Autism Institute, Krasnoyarsk State Pedagogical University. An author, visiting lecturer and speaker, she also has two adult children on the spectrum.

Although autistic children experience the same range of emotions, they sometimes have difficulty in expressing their feelings in a way we can understand - and it's even harder for them to name or define individual (often confusing) emotions.

It may be puzzling to interpret why the child is upset/anxious/scared, but we have to remember that the child is puzzled themselves. Firstly, they have to understand or interpret their own body messages (since all emotions start as inner sensory sensations in the body); then there's the task of translating them into expressions; followed by the even harder task of relating these expressions to other people. It's a big undertaking.

When you see your child's upset, it requires some detective work to find out what is going on, and this is not an easy job.

Firstly, you may need to rule out serious medical problems, even if the child is unable to show he's in pain (e.g. toothache, earache or abdominal pain).

You also need to look at what's potentially upsetting in his sensory environment. You may not be able to see/hear/smell the problem yourself, but that's not to say it isn't a problem for them. Remember also that what's pleasurable for you may be upsetting (or even painful) for an autistic child. Lack of structure or predictability can make a child anxious, too.

However, even taking these into consideration, there remains a major potential trigger - the 'emotional environment' and/or the emotional state of the carer/teacher.

As most autistic children's senses work in 'hyper', and feelings start as sensations (either conscious or subconscious), it is no wonder that many autistic people are emotionally hypersensitive: both negative and positive emotions may cause them emotional overload.

Some children resonate with the emotional states of those around them. Sometimes, the emotional state of a carer can trigger challenging behaviours in these children, as they feel the negative emotions of their carers but cannot interpret what they are feeling and why. These children *sense* any negative signals you may be emitting at a subliminal level.

This emotional sensitivity can be experienced through internal triggers too, such as memory flashbacks. Autistic people can experience emotional scenes from their memory that pop up from nowhere, triggered by something seemingly random.

If it's a sad memory, it can replay itself in the child's mind as if it has just taken place. The child drowns in these emotions and can burst into tears. It doesn't matter that the event happened years ago, it still feels present.

In this case, it's important to stay with the child but not overwhelm him with your concern. Be calm and show understanding - but let him cry, and get this unpleasant feeling out.

To help our children, we have to teach them the language of emotions, explaining facial expressions and body language, inner sensations and giving them the ability to be able to recognise and 'name' each emotion. Help them to link the names of the emotions with their inner sensations and their outer expressions by 'labelling' them as you witness them in your child and in other people, too. Having the language (whether verbal or symbolic) to convey emotion takes you one step closer to an understanding of it.



Together for autism

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

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 - 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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enquiries@togethertrust.org.uk

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The Great Behaviour GOAL

What do I do when my autistic child plays me up? Are the rules different because of autism? Those are questions we hear a lot. Guess what? The naughty step doesn't work for autistic kids! It's time to rethink the rule book and tweak your parenting style. Here's how...

Lining the Pitch: Creating Boundaries

Before assuming that something is intentionally naughty, check that your child is aware that what they're doing is 'wrong' or can actually help it. Often with autism, this isn't the case.

Setting achievable boundaries is all about creating good understanding on both sides. Never assume that an autistic kid just 'gets' it. Be prepared to point out the obvious.

Newsflash number one, autistic kids won't do what you say just because you're in charge. Rules need to make sense to them and have some sort of consistency.

If you say 'not at the moment' - then when?

Every Match Needs A Referee

So should we give autistic kids the same boundaries as others? YES. Why?

- Autistic kids aren't any more capable of judging what's good for their health and long-term wellbeing than neurotypical kids, although they can give a very good impression of seeming like they are!
- Learning to abide by boundaries imposed by your parents is the first rung on the ladder of self-control, something everyone needs to learn
- Boundaries provide routine, safety and security - extremely important to autistic kids
- Boundaries at home can provide a safe way of understanding what's expected in the real world
- Boundaries teach us how to treat others

The difference is, we might need to place different levels of demands on them to get to the same place. We might need to do more explaining to get to that place, too. We certainly need to do more listening.

You are your child's most influential teacher. So the boundary setting job is first and foremost yours. Own it!



Play Fair: This is Autism

If you don't prepare an autistic child for a change of routine in advance, you shouldn't be surprised if they get upset. One of the key features of autism is a dislike of change which is sometimes accompanied by huge fear. Taking them to a party with a hundred people present and expecting great behaviour might be achievable with one of their siblings, but this represents a very real threat to an autistic child. So prepare with photographs and Social Stories™, warn of changes, keep visual reminders and don't expect as much in terms of how long they can stay (or even whether they can cope at all).

The same goes for other challenging sensory environments. This can mean anything from bright lights to loud noises or just crowded places. You're right to see disruptive behaviour in these places as 'auty not naughty'. System overload really isn't their fault.

In these cases, think about what could make life easier. A quiet place to retreat to like a pop up tent outside? Ear defenders? Sunshades?



A Two-Sided Match

It's difficult to give autistic kids boundaries for these reasons:

- They may not understand the social rules they've 'broken'
- They genuinely may not be able to help some of their behaviour
- Rigidity may make them inflexible to change
- Their reaction to not getting what they want can be quite extreme/embarrassing
- We can feel guilty if we make our autistic child unhappy
- An autistic child certainly has the staying power to make you pay for it for longer!

Establish clear boundaries

Help them to use their own judgement by asking them questions after an event (with paper)

Good Referees Don't Shout

Shouting is counter-productive with autistic kids. Processing words when emotions are high is nearly impossible. They are so sensitive to the emotional 'temperature' of others and their responses can be so extreme, that once you've started shouting you can pretty much guarantee that you won't be heard let alone understood.

Behaviour can get worse before it gets better. Stick with it.

Offside Confusion: Do They Know the Rules?

Other kids may learn just by watching. For autistic kids we need to be a lot clearer about what's expected of them. Autistic kids learn in a very literal way and may innocently take a behaviour that's appropriate in one environment and conclude that it's ok in another setting.

So, as far as possible it's important to see the world from your child's viewpoint, find out what they know about how their own behaviour has rewarded them in the past and try your best to put the jigsaw together and understand why they would think it 'logical' rather than naughty to behave in this way. Here's where listening to them and a piece of paper and pencil can come in handy. Don't assume that they knew it was 'bad' and did it anyway!

Give praise often and catch them getting it right!

Dodgy Pitch: Can They Help It?

When I see a monster stomping towards me, I don't give an articulate explanation of what it looks like and what my fears are. I just scream my head off. Panic makes me non-verbal and it's the fastest way of getting my message across. Sensory overload might not look like a physical attack, but that's exactly what it is. So if junior screams in a public place, he or she might me in genuine distress.

Offside!

You can often gently redirect destructive behaviour. If you don't like the little one ripping wallpaper, then give him a bin of paper to shred. Be aware that a lot of unwanted physical or destructive behaviour is caused by inadequate feedback messages from the brain to the body and can be improved with the help of a 'sensory diet' provided by an occupational therapist (O.T.), that is physical games and exercises to target that particular need.

Keep calm

Give non-verbal children a means of expressing frustration and negative thoughts

Decide what's at the top of your list in terms of disruption

Making it clear when something IS allowed is as important as making clear when it isn't

Be A Good Coach: Address the Inflexible Nature of Autism

We know that autistic people find change a real challenge. Our brains can adjust easily to change because we know what's important about our environment and what to ignore. Autistic brains do not sift information as easily and are often on red alert.

Change, however, is a part of life and avoiding it entirely does the autistic person no favours. It's the fear of change rather than the change itself that worries an autistic child. If you avoid change entirely, you're feeding the fear.

Ensure that you make positive changes so that your child doesn't always think of new things as something nasty. If you're about to go somewhere different, give them an exit strategy to build up trust and stand by it. E.g. "If you still want to leave it after 15 minutes, we'll leave." Stick to that, however much of a pain it is.

Make changes gradually, slowly and with ample warning. Emphasise the things that will stay the same. Underline the positive aspects of the change that is happening. Build up a diary of changes that have happened in the past, what the fear felt like at first (scored out of ten) and what actually happened after the change had taken place (scored out of ten). In this way you can show your child solid evidence that their fear of change is a greater threat than the change itself.

For a pre-verbal child, use photographs and other images to warn of change.

Visuals are essential. Write it down, stick a chart up – make it physical, concrete and visual.

Make sure consequences of bad and good behaviour come straight after the behaviour itself.

Further reading from our free archive for subscribers:

AuKids Issues 3 and 15: Expert advice on sleep issues
Issue 14: Keeping Calm
Issue 17: Say No Without the Volcano
Issue 19: Self Regulation

Red Card

If behaviour is for attention, once you ignore it, it might get temporarily worse and then if you keep ignoring it, it disappears. Behaviour that isn't attention seeking takes place no matter who is around or no matter how long it's ignored.

Reward a child with huge praise the moment they are NOT being aggressive. Once it starts, stop interacting and interrupt it swiftly and calmly. Don't give any attention for it – even shouting is attention.



Upset the Goalie? Don't Feel Guilty

Feel guilty about giving boundaries to an autistic child? Remind yourself that their long-term wellbeing and how they get on with other people will be massively enhanced by your work. No-one wants to see a child upset but if you suffer massive guilt every time you say 'no', an autistic child is very capable of realising it and capitalising on it. People who grow up without boundaries lose their way. So give them clear direction and a big hug when they make an effort!



Trophies V Penalties

Good behaviour reinforcement works the best with autistic kids. Why? Because it's definite. They know what to do, because they've just done it and got rewarded for it! Rewards are a bit like shouting, though – too much of it and you start to ignore it altogether. Build up to one big reward by using marbles in a jar, or a star chart. Be clear with your child about some key targets that you'd like to work on and make it known to their school, too. Non-verbal kids can also benefit from simple charts accompanied with lots of praise. Just make sure you attach the reward sticker straight after the event.



Keep the same boundaries at home as they have at school

Foul! Tackling Violent and Aggressive Behaviour

Aggressive behaviour can be a result of:

- Frustration at lack of ability to communicate
- Physical pain that can't be expressed
- Emotional distress caused by change
- Social confusion
- Flexibility issues
- Sensory distress
- Lack of sleep
- Lack of awareness



With all the above, getting strategies in place is a must. Preparation, writing Social Stories™ and using books that give techniques to help with flexibility and self-calming are all helpful, plus sleep counsellors can help with the issues that cause fatigue. It takes time, but once you have strategies in place, the groundwork is done.

Some Tips for Giving Non-Verbal Children Boundaries:

- Give simple symbols backed up with signs and gestures
- Be consistent, you may well need to reinforce the message many times
- Give clear 'no' signs and symbols and reinforce with body language and tone of voice
- Don't tolerate aggression, but provide plenty of opportunities for them to communicate ALL their thoughts, not just positive ones.

For behaviour that isn't socially acceptable but has a sensory root, seek alternatives that answer the same need rather than trying to wipe out the behaviour entirely.

Unlocking the Voice Within



FOR more than forty years, Phoebe Caldwell has been working with autistic adults and children who have complex and multiple learning difficulties. Her skill is in engaging people who seem beyond reach and teaching others to do the same.

By Debby Elley

IN 2009, Phoebe Caldwell won the Times/Sternberg award for her work to improve the outlook for people with severe autism. The award celebrates the achievements of people aged 70 or over who have done most for society and good causes in their older age. The author of nine books, now working on her tenth, six years later Phoebe seems to show no signs of slowing down.

She still travels the country teaching her methods to audiences of parents and professionals and strives to go wherever she's needed. So, what drives her?

"Because there are a lot of people with autism: we need to teach as many people as possible how we can engage with each other so that we can all live fuller lives. We learn from them, they learn from us and then we show others how to do it. Age is irrelevant really, as long as one goes about establishing communication in an empathetic way".

She started her career as an occupational therapy helper in a hospital, where she was put in charge of a room full of about 11 "big, very disturbed men", most of them on the spectrum. "My job was to keep them quiet. At that time, about 45 years ago, it was not clear how to engage these people at all. So I was looking around desperately to find ways of – I think survival, actually! Chairs and tables were going in every direction and it was just absolute chaos".

Forty-five years ago, recalls Phoebe, it was all about containing and

controlling rather than interacting. Nothing was really known about engaging people with severe disturbed behaviour and with autism.

"I talked to a psychologist and she said there are two things we know. One is, don't over-stimulate. The other is to try and find out what they actually enjoy doing, if there's anything at all, and work from that. This was quite advanced for the time".

Having built on those ideas, Phoebe started working in other hospitals and eventually got a Rowtree Fellowship to study best practice and teach around the country. Geraint Ephraim was her supervisor. He was the first, she says, to explore the use of body language instead of equipment to communicate with people who were non-verbal.

"He pointed out to me that actually we are the best pieces of equipment we have for interaction - and that's where it all started".

"Forty-five years ago, it was all about containing and controlling rather than interacting".

Phoebe is best known for using a communication technique known as intensive interaction, but she's keen to emphasise that it is only part of her approach. Before intensive interaction can begin, you need to unblock communication channels that have been compromised through sensory distress.

Her approach is called PAVE - Producing An Autism FaVourable Environment. First, you reduce the signals that a person's brain can't process by addressing their sensory issues. Then, you increase the signals that it can manage. One aspect of increasing signals the brain can cope with is intensive interaction 'which is using body language to communicate'. The other is introducing more physical activities, like trampolines, to give proprioceptive* feedback.

I suggested that when trying to reduce sensory distortion, it must be quite difficult to know what's going on in a child's mind.

"I don't think it's hard, you just tick them off. With vision, you look to see if they're screwing up their eyes. If they are, it may be due to visual hypersensitivity known as Irlen Syndrome. I worked with a 16 year-



Olly is listening to his breathing rhythm. He needs to touch faces to know people.

old who was screwing up his eyes at bright light, sent him for a colorimetric test and he came back with blue lenses. He was subsequently moved from the slow lane in his special school to the talented stream and later had to be moved to a school for extremely clever children because his teachers couldn't keep up with him. He was being held back because of something attributed to autism but in fact it was a physical disability.

"It's the same with sound – the Bose Quiet Comfort 15 noise cancelling headphones are designed for helicopter pilots and they cut out about 80% of background noise, but not speech sounds. It means that children who can't relate to their staff because of all the other noise going on can do so. They can tolerate overlapping speech and too many people".

Watching for a child wincing, says Phoebe, is 'a dead give away' for a particular sensory problem.

After addressing sensory concerns, it's a patient, watchful process to find the best language to reach each individual. No size fits all. It's a question of picking up on meaningful signals. Phoebe seldom uses words but gestures, sounds, movement, touch and even breathing rhythms. The results are sometimes startling and always moving.

"I saw a girl with autism recently who compulsively jerks her head and upper body," Phoebe tells me. "The things that she was doing were not interactive. She also has a visual impairment and she likes lines and anything that moves. I particularly noticed this when she was looking into a window with a dark background so she could see her reflection. She was moving up and down, up and down - and then changing the movement from side to side."

At first Phoebe tried picking up on the girl's sounds. "It made no impact at all. So I placed my hand on her back and when her head was going up and down, my hand went up and down on her back. When she was going across, my hand went sideways. I was reflecting the pattern of her movement. It wasn't copying her but was near enough her motor pattern to be recognisable. She recognised it and it confirmed for her what she was doing. She became completely still and attentive for about five minutes".

Intensive interaction, she agrees, is a widely misunderstood technique.



STUCK IN A LOOP: In her talks, Phoebe recalls receiving a beautiful train set when she was young, which she loved. She got a little bored, however, with watching it on a continuous loop – until someone gave her a set of points. "Then it could go in one of two directions and it was much more interesting," she says. "Really that's what we're aiming to do with intensive interaction: we're giving the child's brain an alternative route so that they're not stuck in their repetitive loops".

"It's not just about copying them. The problem with just imitating is that the brain can get bored and it doesn't have that little jolt of surprise which gets them coming back for more. You do have to establish this bridge, so that the brain learns "every time I do something I get a response".

The beauty of intensive interaction is that you only need yourself. "If you use equipment, their attention and yours will focus on the equipment. What actually helps them to relate is interaction, which you have to do using the body language. You use signals that the brain will recognise without having to go through an elaborate processing system".

Why does this type of interaction work so well? "People with autism have difficulty in interpreting what they're doing and who they are because of their sensory difficulties," says Phoebe. "When we use their body language, we are using communication which is hard-wired in and therefore we actually confirm them and help them to know what they're doing. So it brings coherence to a world where they've lost all sensory purpose".

She gives me another example, a non-identical twin boy who dominates his brother. "He had had glue ear, so I don't think he had got used to listening to things and he certainly didn't respond to sound. He was running around all over the place, indicating he was low on proprioceptive input. So we put a wide Neoprene belt round him to add pressure. His mother stood him in front of her, with him facing away from her and we put pressure on this belt".



When responding to sounds doesn't help, firm pressure also provides a recognisable message for Sam.

When the boy made an 'Ah ah!' sound, his mother gave two tugs at the belt, as an answer. "He became completely quiet, stopped trying to pull away, turned to her with a smile and pointed to her face and then put his finger on her lips. That I think is the first time he realised where her sounds were coming from and he was really relating to her. Again, I was tapping into a rhythm that was instantly recognisable to his brain".

Using these techniques, breakthroughs are not uncommon. "I don't often come across a child you can't find a way of relating to. But they may not hear - in his case he wasn't used to listening to sounds as meaningful until he got an associated proprioceptive jolt which echoed the rhythm of his sounds.

"So I start with their movements, particularly the rhythms, but very quickly you need to add some slight difference in order to get them to come back for more".

Perhaps most touching of all is when a voice finally emerges and the first thing expressed is quite unexpected.

"In five cases I have worked with, the first thing those people have said is 'I love you'.

"They are saying we *do* love people and we *do* want to engage with them, we *do* feel lonely - but what we can't handle is this sensory feedback.

"What I find amazing is that we've been simply ignoring those sensory distortions for so long."



Peter is giving himself feedback by tapping his feet. Phoebe joins in the conversation by giving him feedback on the sole of his foot.

* The sense of proprioception sends messages to the brain from the muscles and joints, giving people an awareness of their bodies, quite literally a 'sense of themselves'. When it's low, children tend to move about a lot to try and produce more feedback.

Want to Know More?

Using Intensive Interaction and Sensory Integration: A Handbook for Those who Support People with Severe Autistic Spectrum Disorder - Phoebe Caldwell with Jane Horwood. Published by Jessica Kingsley. £14.99 www.jkp.com

The images in this feature were all taken from **Autism and Intensive Interaction:** Using Body Language to Reach Children on the Autistic Spectrum by Phoebe Caldwell - Published by Jessica Kingsley Publishers at £17.66 and available from www.jkp.com

Other titles by Phoebe Caldwell can be found at www.jkp.com and www.pavpub.com

The Sally-Anne Test



Researcher Simon Baron-Cohen argues that impairments in the development of a Theory of Mind may underlie the social, communicative, and imaginative impairments of people with autism since a Theory of Mind is necessary for normal development in each of these three areas.

In this famous test the child is presented with two dolls (Sally and Anne) a marble, a box and a basket. Sally puts her marble in her basket and leaves the room. Anne then moves the marble from the basket to her box. Sally returns and the child is asked "Where will Sally look for the marble?"

Baron Cohen and his research team found that non-autistic four year-old children could correctly state that Sally would look in her own basket whereas children with autism would point to Anne's box, suggesting difficulty with Theory of Mind.

The Frith-Happe Animations



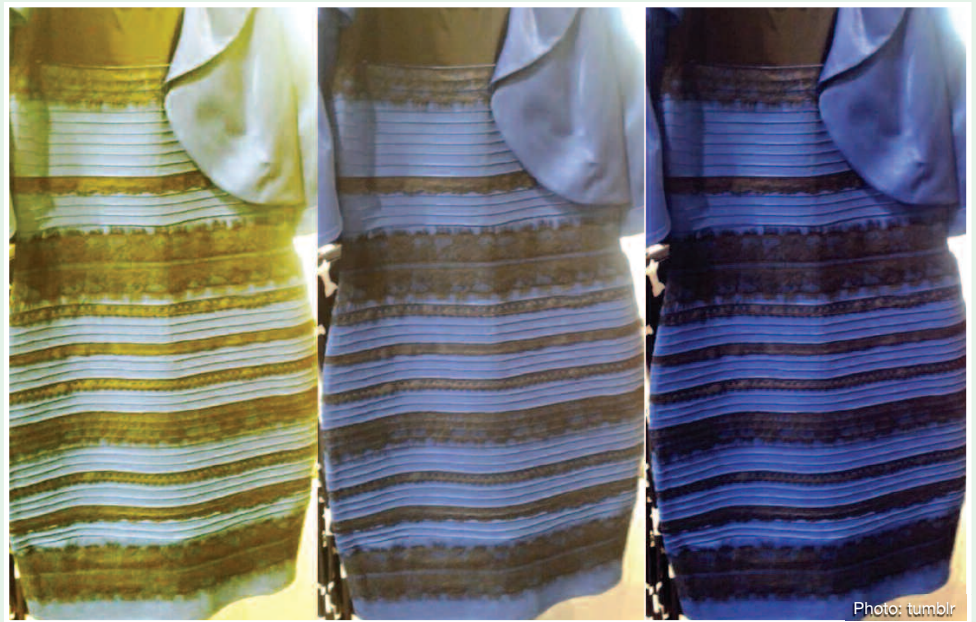
These depict two triangles, one large and red and the other small and blue, interacting with one another in increasingly complex ways.

In the most complex animations, they convey social actions - they appear to be fighting, dancing or mocking one another through their motions.

The animations are designed to test Theory of Mind in people with autism.

The researchers found that people with autism could recognize and focus on social triangles to the same degree as non-autistic people could and were even able to adopt the triangles' perspectives. It's only at the final stage — correctly interpreting the social interactions — that they faltered.

WHAT IS THEORY OF MIND (3D THINKING)?



ON NO, IT'S THAT DARN DRESS AGAIN!! For the three of you who haven't seen this doing the rounds on Facebook and Twitter, it's a dress that the brain appears to see as either blue and black or white and gold.

The AuKids co-editors had a right row about this dress. Tori was convinced it was gold and white (on the left and middle) whereas Debby saw it as blue and black, with the left hand picture just being a faded out version of the photograph on the right.

We were each convinced of our own perspective. What caused puzzlement was to be told that others could see it differently. We each assumed that the other saw it in the same way.

We had to be told that there was a different view. Even then we had trouble believing it.

In a concrete way, this dress has shown us non-autistics what it's like to lack **Theory of Mind**.

Being able to interpret how others think and feel - or what they know - is called Theory of Mind and it requires flexibility of thought. In our mind's eye, we are able to jump into someone else's shoes. People with autism have trouble imagining others' perspectives. But whereas there are only two ways of seeing this dress, there are countless interpretations of human behaviour.

If we didn't know that this dress could be seen in different ways, we'd make false assumptions.

We'd talk at cross-purposes, Tori would possibly be matching the dress with white shoes and Debby would be assuming she'd had a taste bypass. The key piece of information - the fact that we have different perspectives - would be missing.

This is what often happens with autistic people when they assume that you already know what's in their own mind and act accordingly. It may look like they aren't curious to find out more about you. It may seem as if they aren't interested in why you act the way you do. But it's because this requires a leap inside the brain that is too hard to make. This is why empathy is difficult for them to show. It doesn't mean, however, that they lack feeling.

.....
“In order to develop your 3D imagination, you firstly have to know that other people think differently to you.”

Some researchers point out three distinct abilities within Theory of Mind:

- Knowing what someone is seeing
- Understanding how they are feeling
- Knowing what someone thinks (the most difficult of the three)

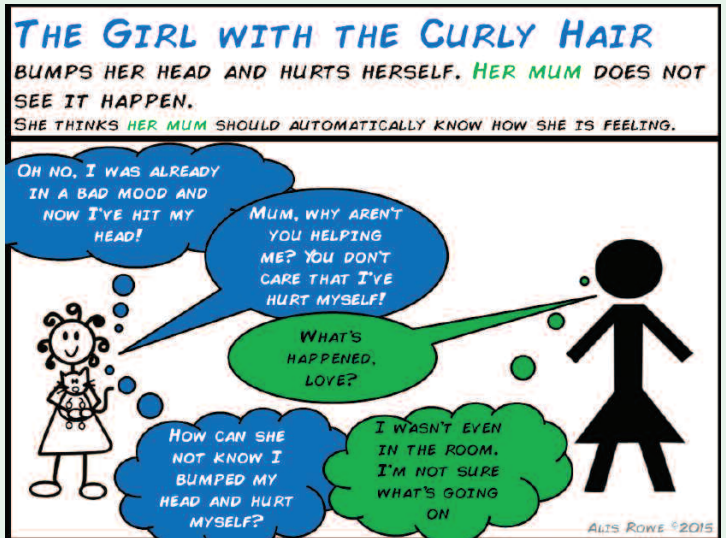
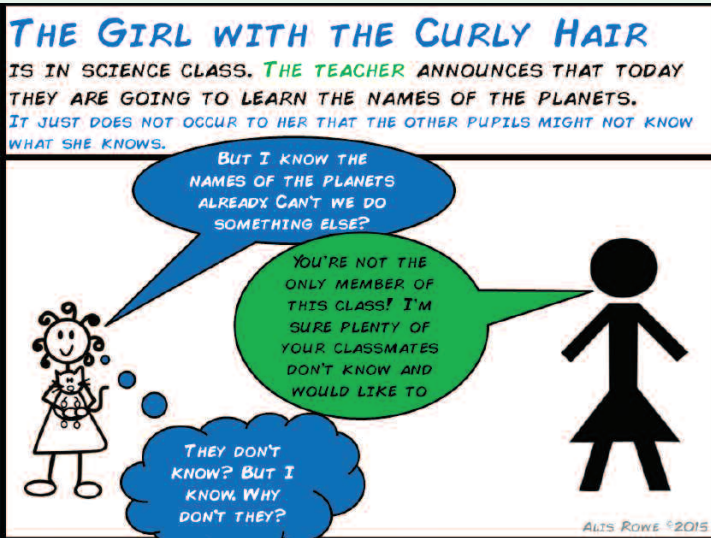
Why do people with autism lack Theory of Mind?

In her research, Uta Frith found that in autism there is less co-operation between the visual areas of the brain and those areas that process social-emotional information. They just don't 'talk to each other' quite as well as in neurotypical brains.

That doesn't mean that autistic people don't have the same feelings as anyone else or cannot recognise feelings in others. Where they struggle is connecting feelings to causes. Compensating for a lack of Theory of Mind can be really draining as it takes an effort of will to try and understand others' perspectives.

In fact, as Alis Rowe (aka The Girl with the Curly Hair) puts it 'We might have less empathy initially than neurotypicals. But this disadvantage actually causes us to work even harder to understand all the thoughts, feelings and behaviours that come intuitively to neurotypicals. Consequently, our capacity for empathy may be much greater than theirs'.

We take for granted what Peter Vermeulen calls our 'empathic switch' - the ability to relate to someone else's state of mind at any moment. We automatically click into that 'mode' when we need to. Autistic people need to be given better prompts before they are able to realise how to respond.



The Curly Hair Project (www.thegirlwiththecurlyhair.co.uk) strives to improve understanding of autism and Asperger's through cartoons. Sign up at the website to buy books and access articles, videos, podcasts and blogs.

A Lack of Theory of Mind is the reason why people with autism are usually better at systems (the 'systemising' brain as Simon Baron-Cohen calls it) and tend to be more interested in things or animals than people (unless it's facts about people). Systems are definite, predictable and structured. Human behaviour is open ended and has almost endless variations.

If you ask someone a question, how do you know what they'll say back? And if you don't know, how can you be confident that you'll respond appropriately? Social situations are overloading and demanding. People aren't comforting to be around, they're frightening.

In order to develop your 3D imagination, you firstly have to know that other people think differently to you. Once you've realised that, you need to be curious enough to ask what they see and feel.

Reading someone else's thoughts is far more difficult to learn. If children aren't taught to assess a situation for themselves and to spot clues in a social context, it can mean that they apply rather rigid conversation rules to situations they recognise.

They might feel the need for a definite script that they can apply, a set of regulations for each situation.

But unfortunately, life isn't a call handling centre. You'd need a million scripts and even then your interaction wouldn't exactly flow.

As parents, we have a role to play in helping our kids to develop skills where Theory of Mind is lacking. We need to be crystal clear in our own communications and recognise the mental jumps that might be difficult, putting little conversational bridges down along the way to help them fill in gaps. E.g. "I'm angry right now, and I'm feeling that way because you didn't do what I asked you to do ten minutes ago".

I think that Theory of Mind is a continuum or spectrum rather than being either entirely present or absent.
 Alis Rowe - The Girl with the Curly Hair

Let's not get too above ourselves, though. If we neurotypicals were so very successful with Theory of Mind, we wouldn't have any conflict at all. We often do. We don't always see things from another's perspective. We don't always choose to. When we lack empathy with someone due to a range of reasons, we make a choice to leave Theory of Mind on the shelf.

Many people don't use Theory of Mind with autistic people, because what they perceive as lack of empathy or awareness makes

them into less sympathetic creatures themselves. This is a sad state of affairs which leaves autistic people more isolated and less understood than ever.

In fact we need to be MORE empathic than people with autism, not less, to allow for social difficulties caused by a Lack of Theory of mind, predict them and be clearer.

Parents tend to use double their empathy skills with their autistic children. It's high time the rest of the world understood and followed suit!

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Further Reading

Peter Vermeulen: Autism Context Blindness (AAPC) – see Review Page 4.

The Autistic Child's Guide: Presenting spark* (Self-regulation Program of Awareness & Resilience in Kids) – Dr Heather MacKenzie (Wired Fox Publications)

Theory of Mind and the Triad of Perspectives on Autism and Asperger Syndrome: A View from the Bridge – Olga Bogdashina (Jessica Kingsley Publishers)

Mindblindness: Essay on Autism and the Theory of Mind (Bradford Books) Simon Baron-Cohen

play it their way



SPIN CYCLE: The animals were left out in the cold when Bobby (left) and Alec played with this farm. The cause and effect sounds and spinning roundabout were much more interesting.

PLAY! "Just the word conjures up images of fun and laughter – that's what it should be like!" says Tori as we start our coffee time chat on the subject of this feature.

The trouble is, that children with autism don't play in the way parents expect them to. This is a real worry when you're new to parenting an autistic child.

Even if you don't have much knowledge of child development, you're aware that play is important. You want to help them to play imaginatively, paint pictures, build things...all that pre-school stuff you're used to.

But playing normally doesn't interest our autistic little ones. They line up cars. They twiddle things. They spin toys. They don't seem to want or need you with them.

Co-editor Debby, whose twins, now 11, have autism, remembers well that bleak feeling: "Alec was three and I bought him this brilliant farmyard. How could a child fail to be excited by this? All the animals made noises. I trotted them in and out of their barns. Alec couldn't give a stuff.

"The other part of this farmyard was a roundabout for the animals. All he wanted to do was watch the roundabout spin. I remember thinking 'What am I supposed to do with this kid?'"



Lucy and support worker Mel

Photo: David Laslett

No-one tells you that there's a different way to play with autistic kids.



Autistic kids play differently because they're getting something different out of play.

Other children use play to build on social skills. They already process the world accurately. They know instinctively that toys represent the world in miniature. They have hit the ground running in terms of development.

For autistic children, play serves a different purpose. It isn't socially motivated. Where processing new input may be difficult, their play may involve sensory exploration. It will almost certainly follow a rigid pattern of repetitive behaviour, since predictability can help to organise a mind that struggles to sift new information. The 'obvious' links between toys and the big world outside may not be that obvious at all, since autistic children may lack the adaptable thought needed to recognise objects that are representational.

So our job here is very different and we have to step back with our expectations. When you play, adapt your goals so that they help to fill in developmental gaps.



Helping them to connect

Just you being there, watching what they're doing, is helpful. An autistic child's trust in others, and eventual ability to communicate with them, will stem from the relationship that they build with you.

To develop play and interaction, you'll need to start very slowly, by making it clear that you don't have your own agenda. Sit tight. Do nothing. Just watch. Yes, you may feel bored! See it as imposed relaxation time. Don't play with your iPhone. Just tell yourself to sit quietly with them for 15 minutes.

You may not be noticed at first. Then, they will scarcely be able to believe that you aren't asking them questions or 'making' them play differently. You may think 'Why am I even doing this?' Stick with it. You will start to get a good reaction, we promise. You may even get eye contact. Good start!



Learning to copy

Forget about playing 'schools' - the ability to imitate on a much more basic level is the building block for social skills. If you start copying what they do, it gives them the message that what they're doing is okay, which gives them the confidence to include you more. Copying is a powerful tool, it extends the child's 'bubble' so that you become part of their world. After a while, if their body language suggests they're happy for you to remain, vary it a bit. They vary it back! That's it, you're playing! Don't initiate too much, just stick with following your child's lead.

Handing you a toy is an invitation to join in. Granting you permission to play with them is one of the most fantastic early social signals a child with autism can give.



Developing joint attention

When you follow a child's lead, there's one thing that you can be sure of, and that is that you're both looking at the same thing. This is called 'joint attention'. It's important because when you supply words and you have 'joint attention', you can be sure that those words are meaningful to the child and that they are making the right connection between the word and what they're doing.

For instance with a spinning top, even words like 'fast' 'slow' 'stop' 'spin' and 'again!' can become very meaningful. Describe what they are doing in simple ways. They may not be able to repeat this language; that doesn't mean it isn't going in.



Developing fine and gross motor skills

Just because your child isn't ready to produce a representational

painting worthy of The Tate, it doesn't mean that they can't be equally happy as other children making a big mess with paint or Play Doh. Simply manipulating a paintbrush or poking and squeezing Play Doh is enough to develop motor skills. It's still fun! So don't worry about the end product.



Problem solving

Even with the simplest toys, there are plenty of problem-solving opportunities. Is that marble too big for the marble run? "Too big!" Is that car too heavy for Hot Wheels? "Oh no! Too heavy!" Do we need to press harder to squeeze the Play Doh 'hair' out of the plastic figure? "Oooh – difficult!" These are all learning and language opportunities. Just experiencing, exploring, and learning the key words, is good play.



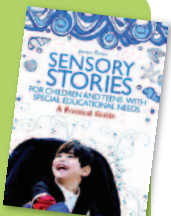
Sophie and support worker Jenna

So forget about playing shops and start thinking about spontaneous engagement and fun exploration together. They are all you need for great play with an autistic child.



Watch Gina Davies' talk on the Attention Autism Programme at www.ginadavies.co.uk
Book: **Motivate to Communicate** by Simone Griffin and Dianne Sandler, Published by JKP.

Sensory Stories for Children and Teens with Special Educational Needs - A Practical Guide by Joanna Grace Published by Jessica Kingsley.



We recommend the **Big Autism Play Day** which Tori attended earlier this year. See our next issue for some fun and practical ideas from the course. Look up www.hirstwood.com/courses-youcan-attend/big-autism-play-day



A Sensory Journey Begins...

Born in Siberia, Olga Bogdashina was a university lecturer and the head of the linguistics department in Gorlovka, Ukraine, before her son Alyosha was born in 1988. After discovering he had autism, she moved to the UK where she gained an MA Ed. in Autism. In the early Nineties she established the first Autism Society and the first Day Centre for autistic children back in the Ukraine. As an internationally renowned researcher and lecturer in autism, she has written books on sensory perception, the theory of mind, communication and spirituality in autism. She is currently Honorary Professor, Programme Leader, Chief Research Fellow and Lecturer at the International Autism Institute, Krasnoyarsk State Pedagogical University. Alyosha is now 26 and Olga also has a 23 year-old daughter with Asperger Syndrome. This is the first of her 'paper' blogs for AuKids magazine.



At the age of three, in 1991, my son Alyosha was diagnosed with autism.

I've never thought of autism as 'good' or 'bad'. The word 'autism' had no emotional connotations for me - it was neutral - the condition I had to research in order to find ways to help my son.

I knew from the start that autism was for life, but it didn't bother me. The main thing was that I wasn't blind to what was going on any more.

The next step was to educate myself to become powerful enough to change the situation to my son's advantage.

From that day onwards, I redirected my research skills from linguistics to autism and started my long journey of learning and discovery.

Prior to his autism diagnosis, Alyosha had been referred to a psychiatric consultation board (by a doctor who had originally told me my son didn't talk because he was 'just lazy'). The board dubbed him 'unteachable', 'unmanageable' and - what infuriated me most - 'hopeless'. He was offered a placement in a special institution for 'uneducable children'.

Did these 'specialists' expect me to accept their 'verdict'?

I concluded that they hadn't got a clue what they were talking about. So I armed myself by learning as much as I could.

After bumping into an American psychiatrist by pure chance who finally gave Alyosha a diagnosis of autism, I started to work with these so-called 'unteachable' children in my school, since they were denied the state education. My experiences both at home and school provided me with a wonderful opportunity to start my first research project in sensory perceptual differences in autistic children.

The reason I chose sensory issues as more important than social and communication impairments was obvious to me.

These children's 'abnormal' or 'bizarre' reactions to sensory stimuli indicated that their perception of the world was different. Differences in sensory perception impact not only behaviour, but also lead to atypical cognitive, emotional, language, communication and social development.

I saw sensory issues as the root of many other difficulties in autism.

These days, sensory issues in autism are widely recognised. As recently as 2013, they've been officially included into the diagnostic criteria for autism - the DSM-V (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition).

At the time, though, nobody took me seriously.

In the beginning I made a mistake, which is quite common even now, in focusing on sensory sensitivities

as the main problem (i.e. being over sensitive, otherwise known as 'hyper-' or under-sensitive, otherwise known as 'hypo-'). I recognised this in my son and in the children I worked with.

However, it soon became clear that these problems are actually secondary, caused by some other sensory phenomena.

It is hard to imagine that some people's senses work differently - they are not blind/ deaf, are they? So they must perceive (see, hear, smell, etc.) the same way we do. Right?

Wrong!

Sometimes autistic children behave as if they were blind or deaf: some touch and smell things to identify them; others tap objects to produce the sound and recognize what it is, because visual recognition can be fragmented and meaningless, or they touch furniture, walls and things to figure out where the boundaries are in their environment.

Alyosha used to smell and touch objects or food to check his visual perception of them. Sometimes he shut down his vision completely and used his ears or nose to 'see' his environment. He recognised the objects by the sounds they produced

much better than their visual images.

The disadvantage of this 'auditory seeing' was that when his hearing became overloaded and couldn't cope with auditory and 'visual' information together, it might either become hypersensitive (and painful) or shut down altogether. Then he found his 'world' unusually quiet (*'the spoon has grown quiet'*) and dangerous. It lead to panic attacks.

Alyosha had difficulty sleeping (he slept for not more than 3-4 hours at night) because what I call 'sound pictures' in his environment made it hard for him to relax. All these experiences caused anxiety, stress and panic attacks.

One sense is never enough for autistic children to make sense of their environment. If there are proprioceptive problems, a child may watch his feet while walking, or his hands while doing something. You can suspect vestibular difficulties if a child avoids climbing, jumping, walking on uneven ground, or embarks on excessive jumping, swinging or spinning.

If an autistic child smells someone who's just entered the room, his carer will no doubt think of the social situation and tell them not to do it, it's not nice.

No doubt it's not nice. But what if the sense of smell is the most reliable sense that the child uses to get information about the world, recognise things and people? Isn't it more logical to address the child's sensory problems first instead of shutting down their only reliable channel?

My son used to smell everything and anything. I'm very grateful to the autistic author Donna Williams who, many years ago, advised me to check his visual sensitivities. Since he started wearing his tinted glasses, he stopped using his nose to 'see' the world, his hearing seemed to 'normalise' and he sleeps at night!

To many young children with autism, the senses of touch and smell are reported to be more reliable. So it's important to let a child use whichever sense they prefer to 'check' their perception.

With appropriate treatment and environmental adjustments to decrease hypersensitivities and perceptual distortions, autistic people can gradually start relying on their other senses.



These days, sensory issues in autism are widely recognised. At the time, nobody took me seriously.





The Last Word

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

Introducing The Unsung Stars of the Show!

LADIES and gentlemen, there are two characters in our story that I've yet to introduce. So without further ado, let's give it up for BLANKIE MARK 1 and BLANKIE MARK 2.

The sorry little bag of stitches on the left is Blankie Mark 1 and the mysterious cocoon-like creature is Blankie Mark 2.

Their importance in Bobby's life is hard to under-estimate. When asked 'Who do you love most, mum or your blankies?' he had to think reeeeeeeally hard about the answer.

The 'Blankies' are people to Bobby. Neither of them are an 'it', they're both a 'he'. The Blankies comfort Bobby at night. They used to go to school with him when he was quite little, but gradually he's accepted that their place is in the bedroom, not trapped in a car door trailing along the A34.

Blankie Mark 1 has enough history to appear on Who Do You Think You Are? It was once Gavin's Christening blanket and in its younger days was a crocheted beauty, looked white and had an actual shape. It accompanied Bobby in the double buggy he shared with Alec, occasionally getting trapped under its wheels. I patiently repaired it over the course of a number of years - in fact my mum and I darned it on her kitchen table once in our best impersonation of a scene from Little Women.



HAPPIER DAYS: Blankie and Bobby have been together since his birth



After about four years I realised that this was becoming a pointless exercise, since there are now more holes than actual 'Blankie'. I may as well try and repair a packet of Polos.

I've suggested a trimmed down version of Blankie 1, but that was (apparently) scandalous. Blankie is washed every now and then and hung up on the line, where it does its best to act like a piece of material. It's basically a huge embarrassment when seen outdoors but fortunately it doesn't have many public engagements.

Blankie Mark 2 is younger and was an effort to replace the frankly post-retirement and barely up to it Blankie Mark 1. Yep, that worked. Instead of replacing the first Blankie, Blankie Mark 2 formed its own special nest in Bobby's heart and now he insists on having both.

Before bed, all Blankie Mark 1 has to do is lie there looking dishevelled. Blankie Mark 2 has an actual career as a Bolster Cushion. In a kind of 'wind the bobbin up' movement, Bobby rolls Blankie 2 in on itself and in a supremely skilful manner wraps the ends to form a perfect cocoon. It can't just be any shape cocoon, it's got to have 'no edges' (!) and be 'perfectly oval and comfy'. It also CANNOT unwind in the night.

Sometimes the cocoon ritual takes about five fraught minutes to get right. When I point out that this is Bobby's own rule, so does it really matter if it gets broken just a tiny bit? - my words are drowned amidst a flurry of white whirling wool.

So there we have it, once Blankie Mark 1 and 2 are ready for bed, so is Bobby. Wherever we go overnight, the Blankies follow. They are sometimes worn as scarves but mostly just being there is enough. How lovely to have so little demands placed upon your person.

If Bobby is 25 and the Blankies come on Honeymoon with him, so be it.

Maybe his wife-to-be will come with her own set.

Things have changed a bit since 1975

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