



Issue 34
Winter 2017

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Positive Parenting for Children with Autism Spectrum Conditions



All Aboard!
How peer training works at school



Family Ties
Getting closer to your autistic relative



Silent Messages
Author Barry Prizant on reading non-verbal signals



PLUS
Researcher Olga Bogdashina on sensory thinking

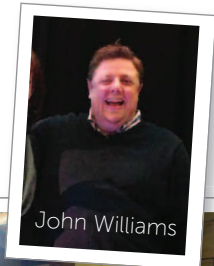


Letter from the Editors

AuKids Scoops Its Second Award!

Happy New Year!

We had a really special year in 2016. In November, AuKids picked up its second gong, the Federation of Small Businesses award for Social Enterprise of the Year (covering the Manchester and North Cheshire regions). It's lovely picking up awards, but more than anything it helps attract funding. This means we can reach more parents and ultimately help more children, which is what



John Williams



AuKids is about.

Also in November, a 200-strong audience packed the main hall at Priestnall School in Stockport for our comedy fundraiser, the stand-up show My Son's Not Rainman, performed by the famous blogger and author John Williams. There were knowing nods and tears of laughter throughout – we are hoping for John's return later this year, but do see him if you can, look up www.mysonsnotrainman.co.uk for tour dates. A big thanks to

Priestnall School and its curriculum support director Gareth Morewood for helping us to organize the event and loaning their hall.

We'd also like to thank the generous companies who supported our raffle on the night - AAPC



AuKids team Jo Perry, Tori Houghton and Debby Elley with FSB awards judge Shelim Rahman.

Publishing, Fins Design and Print, Golden Bear toys, Jessica Kingsley Publishers, Jumping Clay, Michael O'Mara books, Orkid Ideas, Pavilion Publishing, Rosemary Johns, Souvenir Press, Speechmark Publishing, Starpacks, Tania Marshall and Time Specialist Support.

This year, our mission is to host some smaller talks at our own offices. Our researcher Tim Tuff will once more be out and about telling people about his own experiences living with autism (write to us if you'd like him at your support group). See the readers' page for our programme of local events.

To those further afield, we're sorry that childcare keeps us in the North West of England for much of the year, but this magazine is yours, too. If you'd like to review an event that you've attended in another part of the country, please write to us at editors@aukids.co.uk

Would you like to help us receive funding support? Send us a video message saying why you like the

magazine to editors@aukids.co.uk We're making a compilation of them.

Remember that we love to hear from our readers. Send us your pictures for the celebrity spotlight feature and if there's something you'd like us to cover as a feature, we are always delighted to hear from you.

Tori & Debby



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COMPETITION WINNERS FROM ISSUE 33:

- **My Son's Not Rainman:** Nicola Kurdo, Manchester & Laura Hawcroft, Manchester.
- **Uniquely Human:** Jill Hallas, Cheshire & Vitalii Tymchysen, Cheshire.
- **Brainboost Box:** Mandy Potts, Merseyside.
- **Flexible Thinking:** Michelle Hayes, Urmston & Sara Basma, Tiverton, Devon.
- **Pedibal Bicycle:** Alice Dawkins, Somerset.

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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Debby Elley and Tori Houghton

COVER PHOTO AND PHOTO OF
TIM TUFF ON PAGE 3: David Laslett
- www.manchesterphoto.com

David Laslett
DIGITAL PHOTOGRAPHY

PRINTING:
R and P Printers, Dukinfield

GRAPHIC DESIGN:
 periscopestudios
www.periscopestudios.co.uk

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

READERS' PAGE

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

Cover Star

★ Will Bevan ★
Age: 6

Diagnosis: Autism

Likes: Trampolining, swimming and cheese sandwiches!

Dislikes: Places with no WiFi!

If he were Prime Minister: Holidays abroad would be free so he could go once a month!!



Hello, this is a photo of Jack enjoying his snazzy new shiny Pedibal bike we won in your competition.

Thankyou so so much. It was his Christmas present. It's taken 4 days for him to get on it (he kept looking at it out the corner of his eye, as he walked past!).



He does seem to like it now he has finally decided to try it! It's so light and will grow with him.

It's something we never would have been able to afford or consider so thank you so much.

Alice, Mark, Lottie and Jack Dawkins

Crewkerne, Somerset



Jack and his mum Alice 'He loves brushes to flap!'

Make a Date with AuKids Live!



If you live in the Manchester area where AuKids magazine is based, you may be able to spend a lively morning with us at one of our informal talks. They take place at our Old Trafford offices, which we share with Time Specialist Support, from 11.30-1pm and are just £5.00 a ticket, with very limited availability. January's talk from Tim Tuff takes place on 26th of the month and you can book it here: aukids-timtuff.eventbrite.co.uk

New Year Honours for Children's Advocates



Sherann Hillman

Many congratulations to two of our readers who have been awarded MBEs in the New Year Honours list.

Sherann Hillman, head of family services at the Seashell Trust, is also co-chair of the National Network of Parent Carer Forums (which influences policy) and chairwoman of Parents in Partnership (PIPS) Stockport. Her MBE was for services to children with special educational



Jill Sheldrake

needs and disabilities. Sherann has always supported our work at AuKids and we're thrilled for her.

The Together Trust's Service Director, Jill Sheldrake, has also been awarded an MBE, for services to looked-after children in the North West. The Together Trust buys AuKids for its families and has supported us since our first year in print, so we know Jill will be reading!



DATE	TITLE	WHO'S TALKING?
02/03/17	Meet the Editors: How We Make AuKids	Co-editors Debby Elley and Tori Houghton
27/04/17	What's it like to have autism?	Distributor and autism advocate Tim Tuff
25/05/17	Getting the best out of mainstream school	Co-editor and mum of autistic twins, Debby Elley
13/07/17	Working with someone who has autism	Distributor and advocate Tim Tuff
19/10/17	My Sensory World	Distributor and advocate Tim Tuff
November 2017	My Son's Not Rainman	John Williams will return – plans in progress!

FOLLOW US ON FACEBOOK AND TWITTER FOR FURTHER UPDATES

CONTRIBUTE!

We would like to hear about your experience of inclusive places of worship. Please write a paragraph, with a picture if you like, to editors@aukids.co.uk by the end of February.



Reviews & Prizes

MY SON'S
NOT RAINMAN



STAND-UP COMEDY

My Son's Not Rainman

By John Williams

November 16th, Priestnall School,
Stockport (in aid of AuKids magazine).

What our audience said...

This was an inspiring, light hearted, HONEST, heartfelt, funny expression of the life of those who are parents of children with autism. It enabled those who work with children and young people to reflect with humour and relate to the people they work with, respecting their individual 'quirks'. That is what makes them unique and special. It's a must see show for anyone who lives or works with autism. John's refreshing approach showed it is ok to laugh and see the humour, in fact it is essential!
10/10 - *Beccy Timbers.*

'Just a fabulous evening, congratulations on organising it...Haven't laughed so much in years. A fantastic way of sharing the special qualities our autistic community has; everybody could tell how much John obviously loved his son, and how totally accepting he was of his autism. A lesson for all of us in 'normal' world' - *Tony Houghton.*

'We all loved it, hilarious and touching at the same time' - *Charlotte Lawlor.*

'What can I say, I knew I was going to enjoy it simply because of the name of the show but John Williams was absolutely fantastic. From inclusive gingerbread men to exploding chocolate cakes, it was an hour and half I won't forget in a hurry. It was also very moving and emotional at times and it was clear that John cares so deeply for his son while still being able to portray him in such a positive light. He was an inspiration! Thank you to John and AuKids for organising this and congratulations on hosting such a superb event'. - *Keef Eliyot.*

'What a truly magical evening it was. I haven't laughed so long and hard in some time. There were some truly side splitting anecdotes but also a strong message of the love shared between a Dad and his son'.
- *Ruth Thomson.*

'Thank you for organising a fantastic evening! I laughed so much more last night than I did at the Billy Connolly gig last weekend!' - *Jo Billington.*



Dr Elisabeth Hurley

autism west midlands

CONFERENCE

Exploring Autism Interventions: Autism West Midlands' 5th Annual Autism Conference

Queen Elizabeth Hospital, Birmingham, November 28th 2016

Autism West Midlands has been the region's leading autism charity since 1965. I was hugely impressed with this conference. It hit just the right note for parents, with interesting and relevant presentations; in fact, from the viewpoint of a parent, it's one of the most useful conferences I've attended.

Dr Elisabeth Hurley, a research officer for Autism West Midlands, kicked off proceedings with her talk 'Key principles for choosing an autism intervention'. The principles are featured in the book *Choosing Autism Interventions*, which she co-authored with Bernard Fleming and the Goth. You can also have a look at them on the Research Autism website here: researchautism.net/autism-interventions/making-the-decision/principles Guidance when choosing an autism intervention is often thin on the ground, and those who design interventions can make outlandish and untested claims, so this list is invaluable.

After this impressive round-up, Lisa Roberts, who has 15 year-old twins on the spectrum, gave an overview of some of the challenges and triumphs she'd faced. Lisa has started her own business making weighted blankets. You can follow Lisa on Twitter @Lisage12. Lisa has also formed the Jigsaw Family Group and finished with a beautiful quote: 'If you light a lamp for someone else it will also brighten your path'.

I attended the workshop led by Dr Pru Allington-Smith, a consultant child psychiatrist, who gave a succinct and clear overview of the types of medication available to children with autism and why they might be helpful. They are most often used to treat common problems that often accompany autism, such as OCD, anxiety disorders and depression. She talked about alternative types of therapy, such as CBT (Cognitive Behavioural Therapy) and the drawbacks of various types of medication. Overall, her message was that these should be the very last port

of call. AuKids may well work with Pru on an article giving more detail.

Developmental psychologist, Sue Fletcher Watson, Chancellor's Fellow at the University of Edinburgh, was another keynote speaker whose subject was Autism and Technology. She began by debunking certain myths, such as screen time being damaging. Since screen time can cover so many different activities, she told delegates that they should look critically not at the time spent on screens, but what activities were being done. To back this up, she quoted research from Parkes et al in 2012 which found no links between screen time and behaviour and Bedford et al in 2016 which found no relationship between the age of touchscreen usage and developmental milestones.

Quoting further research, she also defied the arguments that technology is addictive or that there is a causal link between using screens and obesity. She urged delegates to consider the mental health of children on the spectrum when criticising screen usage: "What if the one thing you're good at isn't respected by those around you?"

However, she did issue some warnings. We need to give young people the skills to manage their own technology diet, she said. And yes, there is good research to show that late night use of technology can impact on sleep. We also need to provide our children with a variety of opportunities to do other things and they need to be able to understand digital etiquette.

For app reviews by Sue and her team, look up www.dart.ed.ac.uk/asdtech/app-reviews

The well thought out addition of detailed visual instructions on getting to the venue as well as networking badges, a quiet room and plenty of volunteers, ensured a smoothly run event.

Debby Elley,
AuKids co-editor

CONFERENCE

Beyond Autism: What does an autism diagnosis mean?

Hosted by Research Autism
October 2016, Friends Meeting
House, Manchester

This challenging one-day conference uncovered some interesting questions about what a diagnosis of autism actually is and debated the very nature of the label we think we know so well.

Opening the conference, Sami Timimi, Consultant Child and Adolescent Psychiatrist, argued that there was as yet no proven genetic basis for autism and asserted that brain studies were 'consistently inconsistent'.

He put forward many arguments supporting his case that autism is not a medical diagnosis but was nevertheless a helpful classification for some purposes as long as we understood it as such.

His somewhat challenging conclusion was that autism is in fact a social construct driven by a service economy that puts emphasis on emotional intelligence and social competence.

And that was just for beginners. Dr Caroline Bond, Senior Lecturer at the University of Manchester, softened the approach by asking whether an autism diagnosis helps in the world of education. She highlighted a lack of research into providing support in schools. Speaking about the nature of good practice, she insisted that it was the child, rather than their diagnosis, which should be at the

centre of any approach.

Chris Gillberg, Professor of Child and Adolescent Psychiatry at the University of Gothenburg, Sweden, uncovered further difficulties in the standard approach to diagnosis. He argued that although we sift out what we call 'autism', nearly always in cases where there is 'early impairment' there are co-existing conditions. Autism as we see it is merely a simplification of a wider picture and lines between autism and so called co-morbid conditions are far more blurred than we may suppose.

Taking the more personal side of the argument, Kabie Brook, Chair of Autism Rights Group Highlands, spoke about neurodiversity, referring to the neurotypical world as 'a kind of colonialism' which imposes its own solutions on autistic people and talking about the urgent need to take into account the views of autistic (and other neurodivergent) people in more than a 'tokenistic' way.

Francesca Cannas, who has Asperger Syndrome, gave an up-front and amusing talk about her own experience and her concern that a person-centred focus in childhood could discourage autistic children from adapting as adults. Diagnosis, she argued, shouldn't mean that you expect society to change around you - there has to be some give and take.

This left me concluding that although autism is a helpful label, we cannot depend on diagnosis alone to give us a definite pathway for solutions.

Debby Elley,
AuKids co-editor

BOOK

Building Language Using LEGO™

Bricks: A Practical Guide
By Dawn Ralph and
Jacqui Rochester

Published by Jessica Kingsley
£16.99 • ISBN: 978-1785920615

A few years ago I was involved in helping to run some Lego™ therapy groups with the National Autistic Society. These were led by Dr Gina Gomez, who had trained with the originator of Lego™ therapy, Dr Dan Legoff. Legoff developed the idea when he realised how engaging Lego™ was for children with autism and its potential for learning group interaction and co-operation through building together.

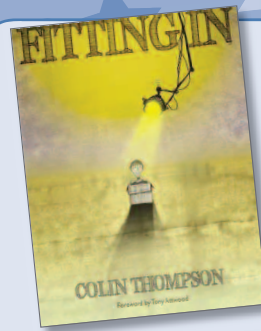
We'd completed the initial training which explained the theory and concepts behind this approach, but there was a lack of resources to explain exactly what to do and how this would improve language and

social skills of young people with autism...until now!

This book does exactly that. It explains exactly what each therapy session will involve and how we can address different language and communication skills. There are continued references to the original Lego™ therapy but it has been slightly adapted. Instead of three children in each group, in this approach there are only two, taking the roles of an engineer and a builder. Each group has a facilitator (the adult) and there are helpful guidelines for them. The importance of supporting each child to problem solve and have 'repair' conversations is highlighted and phrases and strategies to help these are suggested.

This very practical book would be useful for parents, teaching or therapy staff. I only wish I'd had it years ago!

Tori Houghton, AuKids co-editor and
Speech and Language therapist.



BOOK

Fitting In By Colin Thompson
Published by Jessica Kingsley Publishers
£15.99 • ISBN: 9781785920462

In this autobiography, the only time that children's author and illustrator Colin Thompson mentions his Asperger's is in the ingeniously illustrated middle 13 pages. It's a nod to his condition that seems to come from another book entirely and would be fabulous in its own right as the start of a teen book.

I've never come across an author whose neglected childhood is depicted in such an amusing way. The opening chapters are horrifying and hysterical at the same time. The damage that his neglectful mother, not to mention abusive school, caused Colin

becomes only too obvious as his memoir unfolds.

The tone changes swiftly from cynical to lyrical as Colin describes the lonely depression of his early adulthood.

The detail of his reflections are extraordinary and his honesty is unflinching, making for uncomfortable reading at times. Coupled with this is the constant theme of helplessness when emotional communication is required. Running away becomes the common thread that sews Colin's story together and drives his marriages apart.

This fascinating account of a life that moves from dismal to triumphant in a matter of chapters, shows us that fitting in is for some impossible and not even required. Colin's eventual peace comes from the knowledge that his strengths lie in his differences.

The surreal magic of this author's illustrative work accompanies each chapter.

Debby Elley,
AuKids co-editor

Living with autism isn't easy. But finding out all about it should be.

Everything you need to know in one place
www.autismlinks.co.uk



 **autismlinks**

“ My kid has no sense of danger. Am I destined to live my life wishing I had eyes in the back of my head? ”



OTHER PARENTS WATCHING THEIR KIDS AT THE PLAYGROUND



AUTISM PARENTS WATCHING THEIR KIDS AT THE PLAYGROUND

(With thanks to Autism Odysseys)

Your idea of clear instructions may not be the same as your child's, as Alex Lowery explains in his book:

'I had absolutely no concept of road safety or danger. We would stand by the crossing and I'd try to run into the road. My mum would say, "You can't cross the road now Alex, there are too many cars!" However I thought if you closed your eyes and couldn't see the cars that would mean it was safe.

'My mum would say, "No, Alex, wait for the green man to come - you can't cross the road until the green man comes." When the green man came, I'd look, but I wouldn't be able to find him. My mum would point and say "Look, it's right in front of you...there!" but I was actually looking for a real-life green man. I was busy looking at all the people, trying to spot the green person! Everything to me was so literal that even the simplest conversation could become filled with misunderstanding!'



From *Thinking Club: A Filmstrip of My Life As A Person with Autism* by Alex Lowery www.alexlowery.co.uk



Luke Beardon

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

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

Um, possibly, yes - sorry about that! However, I'm guessing that most parents worry about their children all of the time - and that the way in which parents manage their stress over their children (whatever the age) is the same across the board. That is, seeking to reduce *risk* as much as possible in as many *eventualities* as possible, while not inhibiting their quality of life. Life is always risky - and you can double that for the autistic individual (figuratively, not statistically) - so for me it's all about the balance between acceptable risk and a good quality of life.

So - what are the risks, and how can they be reduced?

I guess the easiest way to identify risk is to recognise that in the main they can be split into two categories:

- People
- Environment

And for each of these categories, risk can be in a number of different areas:

- Physical
- Emotional (harm at an emotional level)
- Mental (harm to mental well-being)

The question posed (I am presuming) is based on physical danger, so I shall attempt to address that.

The first thing to do is identify the specific danger and then ascertain whether or not the danger is one that needs a judgement, or whether it's a 'black and white' non-optional definitive 'no' - the latter is far easier to deal with but the former is far more prevalent! The latter might be identified by a simple 'is there a rule already in place? If so, then it's a 'black and white' non-optional case, e.g. putting on a seatbelt in the car.

It may also be very useful to 'turn' judgement decisions into black and white decisions by applying a rigid rule yourself - so it's the rule that needs following rather than having to make a difficult judgement. Examples could include not crossing a road unless it's at a pedestrian crossing, or never jumping out of a window from an upstairs floor (caveats can also be supplied, e.g. the latter rule may be broken if the house is on fire!).

Lastly, for 'judgement' decisions, it might be useful again to impose a rule about who they should ask first. For example about whether to approach a person, eat some biscuits, go into that shop, etc. As your child gets older, you can both start to identify patterns where the answer is always 'yes' or 'no' and the need for asking can reduce.

win...



Bittersweet on the Autism Spectrum

Published by Jessica Kingsley

...one of two copies of Luke Beardon's brand new book, a compilation of personal accounts from people with autism. 'In a world where ASD is officially classified as a 'disorder', this book contains wonderful and uplifting accounts of how autism can be a blessing. The enthusiasm and strength of the contributors shines through in each revealing chapter. A must read for everyone newly diagnosed with the condition and for clinicians who insist on representing autism as a deficit-based condition'. E Veronica Bliss, Clinical Psychologist.

E-mail competitions@aukids.co.uk with your name and address no later than February 28th 2017, quoting 'Bittersweet' in the subject header.



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



Paul Holland

Dr Paul Holland is a chartered psychologist and consultant behaviour analyst who has worked with individuals who have autism for more than 20 years. As well as writing for AuKids he is also a regular columnist for SEN Magazine.

www.drpaulholland.org

I can imagine how difficult it must be in these situations and feeling as if you can never turn your back for fear of your child getting hurt or injured. But rest assured it is a common misconception that children and adults with autism have no sense of danger. Rather, people with autism have an under-developed or at times a skewed sense of danger and as you probably know, often require direct and specific teaching about situations that may be dangerous to them.

There are convincing neurobiological explanations as to why individuals with autism have an under-developed sense of danger (see for example www.dnalc.org/view/1272-Amygdala-Dysfunction-in-Autism). In practical terms, let's think about how we learnt - and continue to learn - about danger.

When we are children (and adults for that matter) we learn about dangerous situations by:

- Experiencing cause and effect. That is, trying something and hurting ourselves, like riding a bicycle too fast around a corner and falling off and grazing our leg. But, because we are fearful for our children with autism we often deter and perhaps subconsciously prevent such experiences. As the expression suggests, *experience is the teacher of all things*.
- Being told that something is dangerous (this requires an understanding of language including what 'dangerous' actually means). So we may

say, "Do not stroke unknown dogs as they may bite you". But language is an area that is a difficulty for individuals with autism.

- Being scolded when approaching danger. For example, when about to run into the road a parent may shout "NO" or "STOP".
- Thinking ahead and imagining a negative outcome. So, something like "If I ride a roller-coaster it may crash like I have seen on television. I could get badly injured or worse".

This sort of thinking is something that children with autism may struggle with.

- Recognising physiological reactions to certain situations, like an increased heart rate or sweating. But in autism bio-feedback may be confusing.

So here are some tips to help overcome these difficulties:

- Allow our children to experience as much as possible. Combine this with reinforcement when they avoid danger, behave cautiously and follow rules.
- Teach our children what is dangerous using ways appropriate to their level and preferred method of communication. Often Social Stories™ with pictures, symbols, text and sound are the best. Follow this by reinforcing with real life experiences and be sure to generalise the experiences, using them in different contexts.
- Provide definite 'hard and fast rules' that never become relaxed. For example: 'Look right, look left, look right again'; 'Click Clack Front and Back' and 'Never run into the road'.
- Explain, again using a variety of preferred methods, about danger and what could happen to them in dangerous situations.
- Be patient and remember that because generalisation is difficult for our kids, we have to re-teach danger in specific situations. For example, climbing a tree may not be the same thing to them as climbing a ladder or climbing over rocks.

It is stressful, but you will get there and eventually will have more time to relax when your kids are exploring the world.

* For Social Stories and how to write them, see Issue 15 on our online archive.



Heather MacKenzie

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

www.drheathermackenzie.com
spark-kids.ca

My goodness, this is a huge issue. Sense of danger covers so many things, from not touching a hot object to avoiding poisonous substances, to not running in front of moving vehicles, to not going away with strangers.

Early in life, children learn by touching, tasting, and exploring everything. We carefully keep dangers away from them and them away from dangers. Children in these early stages don't recognize dangers themselves. This continues through the preschool years for all children. They don't realize that some things are dangerous and they also don't have strong inhibitory control (e.g. thinking 'I've just got to touch that even though Mum said not to').

Understanding of danger and risk continues to develop into adulthood. Teenagers often believe that benefits outweigh the costs of risky behaviour; most teens seem to feel immortal. Some adults seek dangerous situations apparently to experience an 'adrenaline high' (think BASE jumping where they leap from bridges, cliffs, buildings, and other structures using only a parachute or wingsuit).

So... where does this leave us with children on the autism spectrum? In order for children to learn to heed dangers, they need (a) to develop some inhibitory control (that is, the ability to stop their bodies or move appropriately when needed) and (b) to understand and focus on key features that signal dangers.

I won't go into detail about

teaching children to self-regulate their bodies; this is dealt with more extensively elsewhere (see my book *Self-Regulation in Everyday Life* available from Amazon.com). Teaching them to recognize signals of danger can involve helping them to spot symbols for poison on products, appliances that produce extreme heat or electric shock, safe places, etc.

Use your child's visual strengths to go hunting for these signals so he can spot and match them. Make up a type of scavenger hunt where you and your child have a list of symbols and you go looking for them in everyday settings (see the example below). The scavenger hunt will help focus him on the most critical pieces of information (the symbols) and give you opportunities to calmly discuss the need to stay away, combining with 'power' language like, "Stay away you silly poison/flame/car."

You can combine this information into Social Stories™ so your child can review it on a regular basis.

For dangers such as unfriendly animals, teach your child **always** to ask if he can touch a pet before approaching. If no one is present, there can be no touching. Give him simple metrics for judging if something is safe; for example, if something is taller than you, you cannot climb it or jump off it unless Mum says it's okay.

Keep your rules and metrics as simple, clear cut as possible, at least in the beginning. Be as matter-of-fact about the dangers as you can so they don't become adrenaline-inducing; that is, dangers become an opportunity to defy the odds of injury. We also have to be careful not to frighten them or induce phobias (this is why it's good to teach them 'power' language so they can feel in control). Always use positive language (for example, "stand on the kerb" instead of "don't run into the street" or "tell your hands to stay at your sides" rather than "don't touch the dog"). Many children will respond to just the last part of your statement (e.g. "run into the street" and "touch the dog").

Remember, there will continue to be a balance with our children between teaching them about dangers and keeping them away from dangers.





'DISTANT' RELATIVES?

OUR CHILDREN CAN SEEM TO FAMILY MEMBERS AS IF THEY'RE FROM SOME OTHER PLANET. BUT UNDERSTANDING WHAT'S BEHIND THEIR BEHAVIOUR CAN BE THE KEY TO GETTING MORE FROM YOUR YOUNG RELATIVE...

Are you confused about your young relative? They don't turn their head when you talk to them. You try and make conversation and they want none of it. When you talk, they don't seem to listen. They have autism, you know that, but why does it make them seem so 'distant' and is there anything you can do to bring them closer? Read on...

(P.S. We have varied the gender in each question).

She hardly says a word to me. My other grandchildren chat away about what they've done at school.

Difficulties in language processing and social skills are the key factors underpinning autism.

Two-way conversation means that they have to listen, process and answer unpredictable questions. To most of us this comes naturally and happens in seconds, to autistic people it doesn't come naturally and can be very draining. It isn't that they don't want to connect, but that they don't want to invite a conversation that could set them up for difficulties.

Autistic people also struggle to see something from another's perspective and this makes it difficult for them to decide what you do or do not already know.

This doesn't mean that your

grandchild doesn't want to connect with you. Use what she does say as a starting point, and repeat it back to her rather than asking more questions. "You did some maths?" rather than "And what did you do in maths?"

Bear in mind that autistic people have a vibrant, visual inner world and may be heavily involved in their own thoughts.

If they have a special interest, it's worth asking about. Answers to those sorts of questions are going to be far easier to come by and therefore the child will be much more at ease.

Joining in what they are already doing (if they don't object), with the odd undemanding comment, rather than just conversation, is the answer.

Why doesn't he greet me properly?

For most children, hand-waving is a non-verbal gesture that they learn automatically and easily. For kids on the spectrum, copying others is difficult, and waving might take a while to learn. For verbal children, social skills are a factor. They have seen you, you have seen them, they honestly might not understand waving or saying 'Hello'. Over time, these things can be learnt. If something is done purely because of social convention (like waving as a code for indicating 'I acknowledge you'), you may find it missing in autistic behaviour. Adults with autism have painstakingly learnt these 'unsaid' rules.



Why does she tantrum at the drop of a hat?

There's a difference between a spoilt tantrum and an autistic meltdown. Unfortunately, they often look the same.

Tantrums are designed to gain attention, and the motivation is to help the child get their own way. They stop once they have got what they want, or if the audience leaves.

Most autistic kids can't manipulate through tantrums as they lack 'Theory of Mind' – the ability to guess another's motivations, feelings or responses.

We all have 'meltdowns' under extreme duress – when circumstances are beyond our control. This is no different, but because of poor self-regulation in autism, it happens more easily.

In simple terms, the child just can't keep their bigger feelings hidden inside them and wear them on the outside.

In addition, with an autistic child, there is plenty more in the environment that can set off a meltdown. Change of any kind is threatening. A noisy, crowded or bright environment can be physically overloading and distressing.

The best way of handling a

meltdown is to keep quiet and calm, keep the environment low key and predictable and use minimum language (and pictures) to aid processing.

Why won't he let me cuddle him?

Physical proximity can be emotionally demanding for an autistic child. In addition, some autistic children have tactile sensitivities which means that touch is hard to bear. Is there a loving signal you can use, a kind of 'code' that shows affection without sudden touch? In the book *The Curious Incident of the Dog in the Night Time*, Christopher and his father have a hand signal to show their connection – deeply moving to watch in the stage version. Some autistic children do enjoy hugs, on their terms, making the touch more predictable.

Why won't she look at me when I call her name?

When we make eye contact with someone we are inviting in a wealth of emotional information and often this is too much for an autistic person.

It's not that she doesn't hear you, or is trying to be rude.



Illustration courtesy of Jamie Salmons
www.instagram.com/jamie.uk
 Inspired by the image 'Distant Lovers' on
 Deviant Art by Christophe Kiciak (gyaban).

Often people with autism hear what you're saying better when they DON'T look at you. Many people with Sensory Processing Disorder (SPD, nearly always part of autism) find it easier to process one channel at a time. So they will look but not listen, or listen but not look. In addition, they sometimes actually peek, and often use peripheral vision. It's a mistake to think that because they're not looking at you, they're being inattentive.

It can be deeply anxiety-provoking to force eye contact, but some adults have learnt to adapt by looking between a person's eyes, so that they give the impression of eye contact.

Sometimes, she may not turn at the sound of her name

because she's just tuned out. People with autism tune into non-verbal sounds more easily, it's not a natural instinct for them to tune into voices. Use her name and then pause to help her orientate.

Why doesn't he seem interested in talking to me?

For neurotypical people, those who don't have autism, people are endlessly interesting. But people are unpredictable, their moods and faces ever changing, their conversations open-ended and undefined. For autistic people, objects are far easier to focus on.

Your best bet is not simply to focus on a conversation, but to find something that you both

like to do together and comment on it as you play, inviting language but not demanding it. Follow the child's interest. More about this in Issue 12 which you can find on our online archive.

Why is she so stubborn? Everything is on her terms!

Ha ha, yes it does seem that way. Rigidity of thought is part of autism and although you can help to make thinking less rigid – see last issue – fighting fire with fire and demanding change doesn't work.

As neurotypicals, we have to understand that all new environments pose a challenge to a person with autism. Change to an autistic person is scary; rigidity is really a coping mechanism that helps a person hold it together in an unpredictable environment. Trying to 'break' what you see as stubbornness is actually attacking that coping mechanism and may do more harm than good. So pick your battles. What is absolutely non-negotiable? (e.g. safety) and

what is okay?

Gradually introduce small changes, encourage small concessions, explain how happy that would make you, and praise any flexibility. Point out where she has been flexible in the past, and what good things that led to (e.g. she liked a new place that she had feared going to).

He doesn't seem to know why I am upset with him.

In autism there is less co-operation between 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 people with autism don't have feelings or cannot recognise feelings in others. It does mean that interpreting the feelings of others and connecting them to a particular cause (i.e. you are upset because he dropped your priceless figurine) may be tricky. Just be very clear about how you are feeling and why, join the dots for him.

Support for me and my family

Our family support services offer a wide range of advice, training and free advice drop-in sessions



If you are looking for flexible care, short breaks, special education or community support for a young person or adult with an Autism Spectrum Condition (ASC), in North West England, then the Together Trust can help.

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- For our features on rigid behaviour see Issue 10 and Issue 33.
- For our Ask the Experts on 'Meltdowns' see Issue 12.
- For our feature 'How to Build A Path to Communication' see Issue 12.
- For our feature 'Say No Without the Volcano' see Issue 17.



How to Save Energy When You're on Emergency Rations

We LOVE our kids, no question, but bringing up a child with autism can be very exhausting. Here's AuKids' Top Ten tips for when your energy is flagging.

1

Watch your energy bank



By the time you're at the end of your tether, it will take you twice as long to get back on form. Think of your energy reserves as a bank account (we like this analogy and use it for autistic children too). If something has drained you, be aware that you need to 'pay back the balance' by doing something that gives you energy.

2

Think in the present



Especially in the early days after diagnosis, parents spend a lot of time worrying about the future. This involves thinking of lots of different scenarios that may or may not happen. It's hugely draining. Sometimes we have to plan and choose school settings. But things can change very rapidly, and trying to solve problems before they happen is fruitless. Stick with the present and focus on the things you can affect.

3

Say NO



You've had a bad day and yet you've said yes to something you don't really want to do. Can it be easily rearranged without too much disruption? Allow yourself the question. When times are tough, consciously take your foot off the pedal and be kind to yourself. Sometimes we take on a lot when we are feeling good, only to realise that it's suddenly too much. That's okay, as long as you realise that you can't possibly be expected to deliver on the same level when your parenting resources are at a low ebb.

4

Create a half hour window



Create half an hour one-to-one time each day. You don't have to lead the play, just sit with them and watch. We are so used to 'doing' for our kids and planning for them. Sometimes we may even avoid playing because we feel it requires building, doing, preparing. Just be with them, open to their communication, keeping them company. Resist the urge to fidget. You'll be amazed at the bond this creates, even if you feel you're doing nothing.

5

Precious moments



Yes, you need a holiday! But small things on a regular basis can top up your batteries even more effectively. Make sure those little treats are available to you as a carer – great tasting coffee, expensive bath salts... you're worth it!

6

One at a time



If you try and work on too much at once, you become drained and so does your child. Work on only one thing at a time. If you're not getting far, move onto something else. Don't have an endless to do list of developmental goals.

7

Clear your head



Mindfulness sounds like a buzzword and it's a bit of a craze, but boy it works in terms of setting aside the endless 'traffic' of thoughts that block your energy levels. We like www.headspace.com (thanks Jill Hallas for that recommendation).

8

Hand it over



You may be quite capable of all the form-filling, but look upon your resources as highly precious. If someone else can help make it easier and quicker, take them up on the offer. The parenting stuff is something only you can do – the form-filling can be done by others.

9

Ears going numb?



As parents we are highly conscious that we're possibly the only ones with the patience to listen to endless special interest chatter. Because we like to encourage conversation, we indulge it – and that's great, to a point. However, it doesn't mean you have to listen to the same thing until your ears go numb. Schedule a time in the day to talk about a special subject and make that into a visual reminder. This will stop you feeling bad about switching off and your child will look forward to your undivided attention.

10

Hand them over



Don't forget that as a carer you're entitled to respite and you shouldn't feel bad or guilty about it. Children can sometimes appreciate taking time out with different adults and the earlier they do this, the easier it is for them to get used to being with others. The people who help you out don't have them 24/7, so even if it's a bit of hard work, it's very different if it's just a few hours and remember they are being paid! As long as you're confident and happy with the support that you get, make the most of it.

A paper blog by autism expert Olga Bogdashina



Olga Bogdashina is an internationally renowned researcher and lecturer in autism and the author of books on sensory perception, the Theory of Mind, communication and spirituality in autism. Her autistic son Alyosha, 28, is the inspiration behind her career.

Blog 8

What's the Big Idea?

During my teaching career I've been learning as much (or even more) as I've been teaching. This is just one example, when my student Vita (age 9) taught me how to teach maths.

One day we were counting pencils together and she was very happy to point at each while reciting 'One, two, three, four, five, six, seven!' Great!

So, as I drew a circle around the pencils with my index finger, I asked her:

"How many pencils are there on the table?"

Vita imitated me and drew a circle with her finger, looked at the pencils and asked:

"How many? How many?"

"Vita, we've just counted them, haven't we? How many pencils have we got?"

Vita drew another circle around them and:

"How many? How many?"

"OK, let's count again".

Bless her, the girl patiently pointed at each pencil again and 'counted': 'One, two, three, four, five, six, seven!'

"Well done, Vita. So how many pencils we've just counted?"

"How many? How many?"

"Vita, there are seven pencils on the table. Say, 'seven'".

"How many? How many?"

Feeling absolutely useless and mentally disqualifying myself from the teaching profession, I collected all the pencils from the table and started again, putting each, one by one, in front of the girl:

"Look, Vita. It's one (a pencil was put on the table), two (with another following)..."

But Vita furiously grabbed pencil No 2 and 'corrected' me: "It's not 'two', it's 'six!'"

It suddenly dawned on me that instead of counting the pencils as I had expected, Vita had given each pencil a number as a name, according to the labels I had introduced to her in the beginning of the lesson.

The red pencil, which happened to be first in line, got the name 'one'; the green pencil was labelled 'two', while the yellow pencil I'd just referred to as 'two' was actually known to Vita as 'six'.

Vita was keen to learn and to understand what I was trying to teach her, but I was failing her. So our next maths lessons were about 'oneness', 'twoness', 'threeness', etc. It worked!

We all start our lives with sensory experiences. Perceived experiences are stored in long-term memory and form 'perceptual

files', to be used later for reference. We tend to use files for each sense.

With the appearance of language, our formation of concepts changes. Non-autistic children learn to form categories and generalise. They unite things under the same label, so it doesn't matter whether a toothbrush is pink or blue – it's still a toothbrush.

Those categories become filters through which all sensory experiences become organised into classes, groups and types. All sensory information is forced to fit into its most likely category, based on prior knowledge. The outside world becomes represented and expressed in words that can be easily used to create new ideas.

In contrast, many autistic children perceive everything without filtration and selection. That is why they often have difficulty forming verbal concepts.

Even at the pre-verbal stage, autistic 'perceptual files' differ from non-autistic ones. As a result of differences in perception, information about objects, people and events is not organized into a picture that we would call coherent (even if it is to them).

However, this doesn't mean that they remain stuck at the pre-language stage of development. They do develop but via a different route.

Instead of storing general meanings of things and events using verbal language, they construct mental images based on sensory impressions. Once a perception is stored in long-term memory, it becomes a symbol for

a certain object. For instance, if a person has stored 'a ball' by smell, then if a new ball does not have the same smell as the memorized one, it cannot be identified as 'a ball', despite its other characteristics.

This results in autistic hyper-selectivity and a lack of generalisation: the item to be recognised must be exactly the same as the one that was stored the first time.

We categorise our world into verbal concepts, bringing order to everything we experience. Yet for those who have difficulty easily forming these 'verbal concepts' the world consists of unconnected and incomprehensible experiences.

So, different breeds, colours or sizes of cats make each of these pets different 'sensory concepts' as they are perceptually different. They are remembered separately rather than under the general category of 'cat'.

Some autistic children cannot find any association between things that change context. They are able to identify a picture of a cat in a book as a cat, but a cat outside the house cannot be identified as the same thing.

This is why children can sometimes show that they have learnt how to deal with a social situation really well in one place, but are unable to transfer those skills when the location changes.

It is important to teach the same concepts in different situations, with different people, with different objects (relating to the same category), in different places. When this is achieved, it can help to prevent sensory overload and decrease confusion.

My strategy is to refer to difficult situations (e.g. noisy or crowded environments) with labels to help my son Alyosha fight his panic. Providing a 'name' for the chaotic environment is a good tool for him to figure out what is going on and how to deal with it.



KEEPING IT ON FILE

Since some people with autism don't categorise memories into verbal files, their experiences are stored as separate sensory concepts, which makes the world difficult to navigate and overload more likely to happen



A LIFE LESSON THEY'LL NEVER FORGET



Part of GREG LOYNES' role as an Outreach Manager at the Together Trust is to deliver Peer Awareness Training on autism to pupils in mainstream schools. Research shows that this type of training reduces instances of bullying. Here, Greg explains how his training works, and reports on its impact.

One of my roles at Inscape House School is to work with mainstream schools in order to help them better meet the needs of young people with autism.

It became clear early on that not only did the staff teams benefit from autism training, but so did the other pupils. If a school is to successfully support their autism population and provide them

with the best educational experience possible, then everyone needs to know about autism.

Peer Awareness Training (as I call it) has been a really successful way of getting the autism message across to a whole school population and therefore changing the mindset of pupils towards those with

autism. It also highlights the fact that there are many positive aspects of autism and actually it is okay to be a bit different.

Initially, I looked on the National Autistic Society (NAS) website which gave ideas for developing peer awareness. I used these as the basis for my own training and have supplemented them with anecdotes from my 15 years of teaching pupils with autism.

Some schools have asked if I can deliver sessions during tutorial sessions, but I don't think this gives enough time to really address the issues and can feel a bit tokenistic. I now only deliver these sessions as a full lesson, usually in a PSHE (Personal, Social and Health Education) or Citizenship slot.

Before delivering a session, I speak with the school staff to identify if any pupils in the class have autism. If so, we discuss with the young person and their family about what would work best for them. Some pupils want to play an active role in the lesson and talk about their autism, others are happy to be in the lesson but don't want to take part, others don't want to attend the lesson at all.

The Peer Awareness Training sessions are deliberately fun and active. I start by talking about what we mean by the term disability, referring to the type of support that pupils are well aware of, such as hearing aids and guide dogs. We then

discuss autism and how we are going to learn about the condition and how to best support people with it.

We look at the definition of autism, talking about social-communication difficulties, discussing what this means. Then we play a few games so that pupils can experience what it may be like to have autism. When talking about social skills such as an awareness of personal space, we explore how people on the spectrum may need explicit teaching to understand these sorts of things.

One of the games we play is around communication. I start the game by asking for a volunteer who is good at following instructions. I then say I am going to ask them to complete a simple series of tasks, but the instructions are going to be in Japanese! Lots of laughter ensues as the hapless volunteer struggles to follow directions. I give some cues with my body language such as pointing and nodding and the volunteer gets there in the end.

Before we discuss this, I ask for a second volunteer and I give different instructions, this time in Swedish (those of you who are as old as me may remember the Muppets' Swedish Chef, that's me!).

However, this time I don't give any cues through body language. The volunteer clearly is unable to complete the tasks and has no clue what I want



ROLE MODEL: It's really useful to mention successful adults like Stephen Wiltshire in Peer Awareness Training, to highlight positive aspects of autism



them to do. We all have a bit of a laugh about how the first person could do it, but the second person couldn't. Then we consider why this was the case. Finally, I link this to autism and talk about how when someone with autism is in class, it can often seem as if the teacher is talking in Swedish with their hands in their pockets. No wonder they get frustrated sometimes. The session carries on in a similar vein, looking at various traits and playing a game or two to highlight what it may feel like to have autism.

.....

It's great when you can see the kids thinking, 'Hey, this music is pretty cool' as they file into the hall, and then for me to announce that the performer they have been listening to has autism.

.....

The feedback from the sessions has been really positive from both pupils and staff and I've seen the impact for myself. The other week, I witnessed a group of Year Ten boys walking down a mainstream school corridor. Heading the other way was a Year Eight pupil with autism who loves to talk to older pupils and

was often rudely rebuffed.

The Year Eight pupil initiated an interaction. One of the Year Ten boys was rude in return and one of the others said: "Hey, you can't say that, that's tight, he's got autism and is just trying to be social!" The lad who had been rude turned to the Year Eight boy and said: "Oh, sorry mate, I didn't realise." He then offered the pupil with autism a 'fist bump' (check Wikipedia if you're over 30).

As well as presenting the Peer Awareness Training, I also deliver assemblies. These generally focus on autism heroes. Students arrive into the hall as music by artists who have autism is played (James Durbin, Rory Hoy or AutistiX are my current favourites). It's great when you can see the kids thinking, 'Hey, this music is pretty cool' as they file into the hall, and then for me to announce that the performer they have been listening to has autism.

I then share a case study or two on some better known people with autism - Dan Ackroyd has been the most recent example. I talk about autistic 'savants' like Daniel Tammet and Stephen Wiltshire (check out the Human Camera on YouTube). One great activity to do after the assembly is to show the class a picture of St. Paul's Cathedral for 30 seconds and then ask them to draw it from memory. When they have attempted this, the teacher



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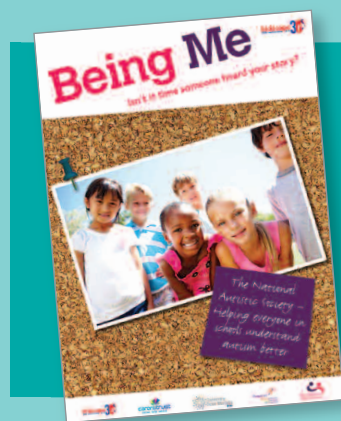
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shows them Stephen's drawing and compares it with their own, it's pretty awe-inspiring and I often get kids coming up to me days after, commenting on how blown away they were by Stephen's work.

None of what I do is rocket

science. It's just making it okay to talk about "that kid" in class and making it clear that he/she has a disability called autism, that everyone is different and that's pretty cool.

It would be boring if we were all the same, right?



Further information

Being Me, is a free anti-bullying classroom resource from the NAS that seeks to celebrate difference and promote inclusion by giving young people in Years 5-8 an invaluable insight into the potential challenges being faced by their peers. www.nas.org.uk/professionals/teachers/resource/bullying.aspx





CONVERSATION WITHOUT WORDS



We refer to some autistic children as 'non-verbal', yet this is a misleading label, implying that they are not sending us clear messages. In fact, children who don't use verbal language are often sending us many signals loud and clear, says Dr Barry Prizant, author of *Uniquely Human: A Different way of Seeing Autism*.

On a beautiful autumn morning, I entered a school in a small town in Massachusetts to do what I have done for three decades as a Speech Language Pathologist* and educational consultant.

This time, I was asked to observe James, a bright-eyed four-year-old child with red hair and rosy cheeks. Only a few months earlier, he had received a diagnosis of autism spectrum disorder following an evaluation at a hospital. James was beginning his third week in his inclusive pre-school programme, and my role as a consultant was to observe him for an hour in routine activities in school, and then meet with the school team and his parents to summarize my observations and provide recommendations.

.....
He used behaviour to communicate. In this case, he was communicating "there is no way I am going into that overwhelming, chaotic room".
.....

As I've experienced so many times before, this youngster was described as non-interactive and non-communicative with significant problem behaviours. Staff added that he sometimes blurted out short phrases that they could not decipher as meaningful, as they could not see any connection to the ongoing activities.

For example, when approached by an unfamiliar adult, he would cock his head to the side and say "Are you a good witch or a bad witch?" I was also told that he used people 'as tools' to get his needs met, by pulling their hands or pushing them to closets that contained his favourite play things such as Lego™ or musical toys. Staff noted with some frustration that he engaged in tantrums to get his way if he

did not wish to co-operate – screaming and sometimes dropping to the floor.

As I began to observe James in his classroom, it did not take very long for me to witness some of what staff had described. He pushed one of the classroom assistants to a tall cabinet and exclaimed twice with great excitement, "It's coming down the tracks!" His speech was barely intelligible.

The assistant looked at me quite perplexed, and I suggested that she opened the cupboard to see what he would look at or reach towards. James immediately shifted his gaze to a plastic box of miniature trains just out of his reach, pushing the assistant's hand towards the box while rapidly repeating "...down the tracks!"

After a few minutes of playtime, when James sat by himself lining up train cars on floor, his teacher helped all the children

stand in line as they prepared to go to a small gym in the school.

As we approached the gym door, I peered through the small glass window and noticed it was filled with mats, climbing equipment and very active, noisy children. As the teacher opened the gym door, a cacophony of sound filled the air, and James immediately dropped to the floor, rolling, grimacing and covering his ears.

With arms flailing and legs kicking, he resisted his teacher's attempts to have him stand up, as he rolled up in a foetal position whilst sucking his thumb. The rest of the class was brought into the gym while one of the assistants sat with James until he calmed down. She then brought him for a drink as he pulled her to the water fountain.

After a full hour of observation, it was crystal clear to me that this youngster, described as non-communicative and



SPEAKING VOLUMES: Non-verbal signals can be very obvious, but in children who don't talk we have to watch more carefully for them.

uncooperative, was attempting to communicate and express his intentions in so many ways. However, because his signals were subtle, unconventional and not always socially desirable, school staff found it difficult to understand what his goals or intentions were.

His teacher felt that she should not allow such behaviour in school, but admitted that her attempts to get him to behave more appropriately had not been successful.

When we met with his parents, I described some of my observations and they smiled and shared that he was enthusiastic about playing with trains. They added that he often repeated sentences they had said or he had heard from videos to request his toy trains or to comment while playing.

His father commented that he often repeated lines from movies, such as "Are you a good witch or a bad witch?" to greet others, which came from *The Wizard of Oz*.

.....

We must make the effort to listen, watch and ask WHY.

.....

I noted that this is called echolalia or speech that is repeated from others, and it is a path to language development for many autistic children due to their strong memory and their unique learning style.

His mother added that since he was a toddler, he physically directed them to specific locations to request objects or assistance. When I described the scene at the gym door, they knowingly shook their heads stating that this behaviour is his language for protesting or refusing when he is unable to speak when confronted with a potentially overwhelming situation.

His mother added that when this occurs, it causes great distress for them in public situations as onlookers believe he is simply a poorly behaved, spoiled child. However, they knew that because he had so little spoken language, especially when upset, he used behaviour to communicate. In this case, he was communicating "there is no way I am going into that overwhelming, chaotic room".

His parents had great insight into how much James was trying to communicate and WHY he engaged in such behaviour, but admitted they needed support and guidance to help him develop more language so that he could communicate in ways that other people could understand.

For too many years, the behaviour of autistic children and adults has been

viewed through the lens of pathology. They have been described as non-communicative, non-interactive and uncooperative, terms that emphasize only what they cannot do, leading to interventions that too often try to eliminate behaviours without understanding WHY the person is behaving that way.

This 'deficit-checklist' approach is not only unhelpful, but it is disrespectful and too often blames individuals whose challenges are based in neurological differences.

What we have learned through decades of research, clinical experience, and from people on the spectrum who can talk about their experiences, is that professionals and parents, and indeed, society in general must change our attitudes and how we view and understand their behaviour.

Ultimately, this will help us provide appropriate and comprehensive support to develop the language and communication abilities that results in successful participation in everyday activities, and that prevents the development of so-called problem behaviour.

Rather than simply trying to change behaviour and 'fix' children on the spectrum, we must support success in communication through the development of trusting relationships.

This requires that we understand that behaviour and all kinds of speech is communication. We must make the effort to listen, watch and ask WHY, and then provide appropriate support. In this way, we will be able to discard the lens of pathology to see autistic people as Uniquely Human rather than broken, by focusing on strengths, abilities and unlimited potential.

*Speech Language Pathologist is the US equivalent of the UK title Speech and Language Therapist

By Barry M. Prizant, Ph.D., CCC-SLP
Brown University
www.barryprizant.com

Credit to Paul Watzlawick, Family Therapist

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BOOK

Uniquely Human
- A Different Way
of Seeing Autism

By Barry M. Prizant
Published by Souvenir Press
£20.00 (Hardcover)
ISBN 978-0285643338

DE-CODING THE SIGNALS

A Personal Experience



Debby Elley,
co-editor
AuKids
magazine

Very often parents know exactly what their children mean by a phrase or a gesture, but teachers and professionals often miss the context when these signals were first formed. Parents have a great advantage in that they were often around when the child first learnt their own signal.

For example, I once thought that my son Alec had something in his eye. Gently pulling down his lower lid, I expressed concern and sympathy. Since then, Alec pulls down his lower lid when he wants sympathy and we now call it 'The Sad Eye'. It's no longer anything to do with something in his eye but is very effective. But if you missed that early distress signal, you'd be in for it!

My other son Bobby knows Toy Story off by heart. When he's upset, he can't find the right words and blurts "I'm lost - Andy is gone!" So-called meaningless echolalia here has a clear purpose, which is to communicate distress and panic. So it sometimes helps not to listen to the actual words spoken, but the emotion behind them.

All autistic behaviour is motivated by a hidden message. However random or nonsensical it may seem, the message is there. Try your best to look at clues within the environment for what that message could be.

Tori, our co-editor, taught me to extend a child's communication ability by interpreting their message and then giving them a more effective means to communicate it. Fine if the rest of the world understands 'sad eye', but they don't.

So, if your child uses their own message to demonstrate fear, show them a symbol or a sign for fear and label that emotion for them, saying: 'I'm afraid'. Use those symbols or signs a lot as your child is giving their own signal, and gradually they will learn to use them spontaneously as a more effective replacement.

Photo © Howard Barlow



The Last Word

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

When helping our kids to learn social 'rules', we teach them to look for cues and signals in the environment to guide them. But what happens when those signals aren't clear to any of us?

Well, what you get is neurotypical mayhem. That's if the concert I've just attended is anything to go by.

My first difficulty is whether I refer to it a 'concert' or a 'gig'. This was an Eighties pop band (ABC) backed by the Southbank Symphonia at a traditional concert venue, the Southbank Centre. A concert then. Not a gig. Yep, I'm confident.

The conductor came on and took a bow, confirming our suspicions.

Once the show started, problems began. Half of the audience were treating this like a classical concert, with the social rules accompanying such an occasion. The other half of the audience were treating it like a gig, with their own set of social rules appropriate for a less formal event.

My brother and I were sitting in the upper circle, on a row that had a walkway in front. As the lush string section started its accompaniment, the 'gig' half of the audience were popping to and fro getting beers, making this not dissimilar in feeling to the Underground station we'd just emerged from.

I was brought up to believe that the merest rustle of a sweet wrapper in the presence of a violin bow is a criminal offence, so was slightly horrified, but my social radar was confused by the presence of an electric guitar on stage. Maybe the gig people had got it right.

What A Performance!

But there was more confusion to come. An interval. The lead singer shuffled off without fuss. You have intervals at classical concerts, surely. So the gig people were therefore mistaken. Your concentration span is supposed to get higher the further up the cultural ladder you climb. So, they should have waited for the interval to get their beer. Stupid people.

Oh well, live and let live, I thought, as the second half began. Maybe we can all find a happy medium without the need for definite social cues.

During the second half, the atmosphere hotted up. The audience, polite if a little remote at the newer material, seemed to awaken en masse as roars of appreciation flooded the auditorium to greet ABC's famous 80s album *The Lexicon of Love*.

Buoyed by this, a couple on the row in front of our gangway stood up and started dancing. The trouble was, whilst the stalls had this firmly down as a gig, the circle audience was the classical variety and really didn't want to do anything but tap their feet. And now it was hard to see the brass section.

"SIT DOWN!" roared a chap behind us. "SIT DOWN!!"

They carried on dancing, but the audience member who had yelled wasn't giving up that easily. He stomped down the stairs. Incandescent with rage, he went and bellowed at them (in a non-concert-like manner, I'd say). They shouted back. There was a lot of pointing. Neither side were

backing down.

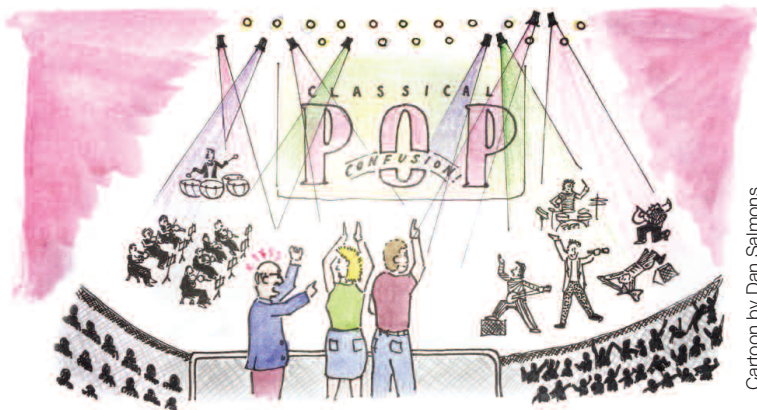
He stomped off and they sat down grumpily, looking daggers behind them. They tried in vain to usher their entire row to get up and boogie, but no one obliged. Later, one of them defiantly stood up again. No one joined him and eventually he had a row with the usher.

By now I was quite happy to accept that it was a gig downstairs and a classical concert upstairs. Highly amused at the entire pantomime, I was scribbling in the autism notebook that resides in my head. This is what happens when social rules aren't clear! People start actually fighting!

So what can we learn from this? Whilst autistic people may have trouble reading a social context accurately, fairly clear guidance is needed for absolutely everyone, particularly in the case where there's no historical precedent. That may well suggest why kids with autism get better at this as they turn into adults – we all learn from experience.

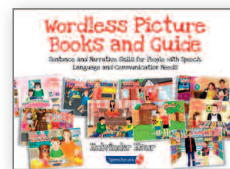
So when your child misreads a situation, think of this: do they really have clear signals? Have they had this kind of experience before? Is your idea of the context and theirs the same?

And anyway, you can't really blame them for any confusion, since evidently it doesn't take much to end up with a punch up at a concert.

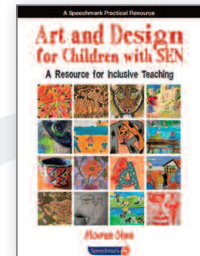


Cartoon by Dan Selmons

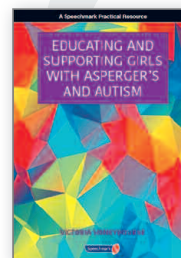
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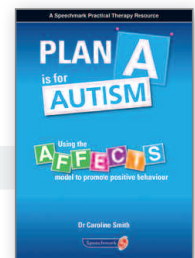
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