

Aukids®

Issue 30
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Positive Parenting for Children with Autism Spectrum Conditions

Meet Julia!

Introducing Sesame Street's first autistic character – See Page 4



Let's Hear it for the Girls

There are more with autism than you think



Your Year Ahead

Full autism events round-up 2016

PLUS

WIN - A Talk with Teddies Communication Kit from The Play Doctors



Letter from the Editors

Debby Tori



New Arrival at Aukids!

Firstly, a big welcome to the newest member of the AuKids team! Tori's baby Remy was born on Halloween – a bit earlier than his due date, but he didn't want to miss a trick - or treat! (see what I did there?). Remy has been given the official title of *AuKids Senior Cuddle Consultant* and will be present at editorial meetings to offer his wisdom (and cuddles).



It wasn't all plain sailing when Remy arrived, as Tori explains: "Everything was going well until at 7 weeks, Remy was diagnosed with a congenital heart condition which required urgent surgery. This was carried out at Alder Hey and Remy, being the little fighter he is, recovered well. He will continue to be monitored but he shouldn't require further intervention. Since then, Remy is settling in to life with me and my two dogs and he loves my singing!"

Thanks to AuKids readers for all your good wishes to Remy via our social networking sites.

Back to you then, and the New Year often brings with it a desire for change. Are you thinking...this is the year I'm going to tackle...*(add problematic parenting challenge here?)*

Before you get too enthusiastic, here's a few tips to help ensure success.

Firstly, timing is everything. January may seem the perfect starting point, but the concept of a New Year's resolution isn't that meaningful to a child...so think about whether this is the right time for *them*.

A good time tends to be when other stresses and changes are at a

minimum. They also have to be ready developmentally. So be flexible. If they're not ready quite yet, just try again later on in the year. It can still be a resolution.

Resolutions can fail because they're a bit too giant. If you break a task down into little steps and give yourself some smaller deadlines to tick off along the way, you're much more likely to succeed. Be generous with your planning – it's more encouraging to exceed realistic expectations than to fall flat at each hurdle because you over-estimated the time, energy and perseverance that something would take.

If you're not sure how to take those first steps, your first task may be to seek out extra information. Recognising you don't know enough yet is a great starting point. Identify your confusion and let it drive you into positive action.

Amongst your resolutions, make one for definite – to reserve yourself some quality 'me' time.

If you find that there's something you struggle with, and you can't find it covered in our online archive, why not give us a shout at editors@aukids.co.uk and ask us to cover the topic?

Have a great year!

Tori & Debby

e-mail: editors@aukids.co.uk

COMPETITION WINNERS FROM ISSUE 29:

- Choosing Autism Interventions book winners: Diane Blood, Workshop; Christine Manning, Chertsey; Amanda Potts, Reading
- Chewigem winners: Rebecca Bennett, Southwell; Khurram Naqvi; Nicola Naylor, Nuneaton. Star projector cube winners: Tam Richardson, Timperley; Lynn Hampson, Mossley Hill.
- Waterfall tube winners: Afshin Tirmizi, Basingstoke; Amanda Ayres, Weaverham; Rachel Kaye, Prestwich.

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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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Dear AuKids,

As founder of the Curly Hair Project, I was delighted to be approached by Marie Claire magazine last year. What a fantastic opportunity to spread the word about my work.

The journalist had obviously been learning a lot about autism because her request to meet me was very autism-friendly. She wanted to know whether I would prefer to speak on Skype or face to face. When I said I was happy to meet with her face to face, she then wanted to know where I'd be most comfortable - a public place of my choice, or my home. She also wanted to know whether or not I was comfortable being photographed by the

MC photography team. When I said I'd rather not, she said that was fine. It was a very comforting introduction.

The interview itself, which did take place at my

house, was very thorough. It lasted nearly two hours and the journalist asked me questions about my whole life. Some of it came out as though we were merely chatting, but some were very specific questions. I was feeling very emotional by the end of it. Unfortunately, I had to relive a lot of unhappy memories that, nowadays, I try not to think about. It will hopefully help a lot of people who felt similar as me. It is that thought that makes it OK.

At 26, I am now much more self aware and comfortable with who I am. When I have my happy days, it is easy to forget how difficult/traumatic the bad days are. The interview was a good reminder to be kind to myself and a positive realisation that, no matter how bad things get or have been, it is possible to come out the other side. I have had some terribly dark periods in my life. There have been lots of times I've considered suicide. But, on the other side of it, and because of my struggles, I have managed to create an organisation that provides comfort to a lot of people, who I would never want to feel the way I did.

Alis Rowe

Managing Director, The Curly Hair Project Ltd
www.thegirlwiththecurlyhair.co.uk
 The Girl with the Curly Hair is one of AuKids' regular illustrators - See Page 11.



This Is My Moment

Tim Tuff is our researcher and distributor. He knows the names of each one of you and says he likes the fact that he's the last person to handle the magazine before it reaches you. He feels this gives him a connection with each of our readers.

Tim has autism, dyspraxia and dyslexia. He joined us as a volunteer when the magazine first started, and has been invaluable to us ever since.

As we've got to know Tim, some upsetting stories from his past have been revealed. His school years were the most unhappy of his life. In the Seventies, little was known about autism in mainstream schools, let alone about how to educate people on the spectrum. Tim says he used to stare out of the window, being unable to do the task in front of him, just waiting for the bell. The experience was made lonely not just because of the bullying he endured from other pupils, but also from the exasperation of his teachers, who did little to help him integrate. His suffering continued until his adulthood.

We're pleased to say that since joining us at AuKids, Tim has blossomed and he now has lots more confidence. So we were delighted to hear that when attending a primary school reunion some 30 years after he was a pupil there, he had the bravery to approach his former headteacher, who had told him he was 'uneducable' and would amount to nothing.

"I just went up to him, placed AuKids in his hands - the one with me on the front - and said 'You were wrong. I've got two

jobs and I now give talks on autism at conferences and to support groups,' said Tim.

"He came up to me later and he told me he was sorry and admitted he'd been wrong about me. Then he gave me a hug. It took more for him to do that than it took for me to tell him he'd been wrong about me.

"Back then, that was the first time anyone had told me I was worthless, and it stayed with me my whole life. Even in recent jobs, I kept thinking I wasn't good enough. I was told plenty of nasty things in secondary school, but that was the first time I heard it and so I believed it. Ever since I have been trying to prove him wrong.

"For him to admit it...I can't explain. It feels as if a new connection has been made in my brain. It's undone some of the damage. I feel free."

Tim's story illustrates something so important. Our kids believe to be true what we tell them about themselves. Good or bad, this judgement becomes part of their inner voice, and it never goes away. If the bad stuff can stick this well, so can the good. So just remember to tell your child how brilliant and clever they are every day!

And well done Tim. Now that's what we call 'closure'!



Wow - Do It Now!

Snow Castle

Gina says: "I am ever hopeful we are going to have lots of snow! If there is no snow, you can do the same activity with a frozen ice castle...but you may need a smaller bucket to fit in the freezer and use warm water".

1 Fill a bucket with snow

2 Turn it out to make a snow castle



Pour on water coloured with food colouring... we used a watering can so it sprays, but a bottle would be fine.

Add another colour



P.S. No sign of snow as we go to print, so use the freezer. Don't forget, adding a bit of juice to ice cubes can make a colourful crunch!

Admire the extraordinary shapes that emerge 3D as the snow castle melts!

Simon Says...

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



Simon's cousin is playing with an exciting toy. Simon would really like a go with it. What does he do?

P.S. Parents: Sand timers are an invaluable investment for this sort of situation - www.specialdirect.com

Dear AuKids,

Last November I won a Gold Award at the Cake International Show in Birmingham. I'm a parent of children on the autistic spectrum and they gave me inspiration to create

the cake on the theme 'Amazing Autism'. Since the show, I've had amazing feedback from parents and children and they are all asking for their own 'Amazing Austin' cake. The main purpose for my design was to make these children and young adults to feel that they are recognised, understood and accepted despite their additional needs.

Yours, Victoria Vertigan.

Risingtotheoccasionby@yahoo.co.uk



Reviews & Prizes



BOOK
Apps for Autism - An Essential Guide to Over 200 Effective Apps!

By Lois Jean Brady
 Published by Future Horizons Inc.
 £33.95 • ISBN 9781941765005

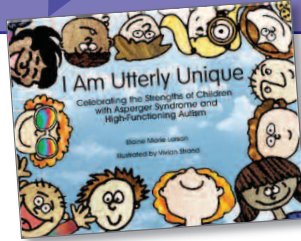
Based in the US, author Lois Jean Brady is a practising Speech Language Pathologist, Certified Autism Specialist (CAS) and Assistive Technology Specialist. Interesting but irrelevant fact: Buttercup, her potbelly pig, frequently accompanies Lois in therapy sessions and is a huge motivator.

We all know that apps can help kids with autism – the question is, which ones and how? Having the right tools without enough knowledge to usefully apply them can be frustrating. This massive book – revised and expanded in 2015 and now reviewing more than 200 apps – is the ultimate resource for inquisitive parents and practitioners. Part 1 covers apps for all kinds of expressive language, including sign language, articulation and Augmentative Alternative Communication (AAC) – those apps that become a voice for kids who can't yet talk. Part 2 is dedicated to building language and language development. Part three covers vocabulary and concept development. Part 4 moves into the realm of social skills and Part 5 includes visual aid apps. Part 6 is for occupational therapy support – including handwriting, bilateral coordination and motor planning. There's even a section dedicated to Neurodevelopmental and Neurological Communication Disorders.

The phrase 'definitive guide' is often an exaggeration, but not in this case. I defy anyone to find an aspect of autism not covered here. Visually easy to navigate with colour coded pages, it's a dream. The only annoying thing for British readers is that the prices are all shown in dollars, but nothing's perfect.

It's available for £33.95 from Amazon – why not get your support group, school or library to stock it?

Debby Elley,
 AuKids co-editor



BOOK
I am Utterly Unique - Celebrating the Strengths of Children with Asperger Syndrome and High-functioning Autism

By Elaine Marie Larson, illustrated by Vivian Strand
 Published by AAPC
 £17.50 • ISBN 9781931282895

I Am Utterly Unique is a large picture book about autism aimed at very young children in mainstream education who have autism or what was once known as Asperger's. Apart from its title, there is more than one unique thing about this book. It's the only book I've ever picked up about autism that doesn't mention one single 'challenge'. The entire focus of this A-Z picture book is what's positive about autism. D is for Detail Detective, F is for Fantastic Focus and V is for Vivid Vocabulary. You get the picture.

In colourful, zany fashion this book tells a person with autism that they have strengths and that they are worth celebrating. Now you may think, hold on, isn't that an unrealistically positive representation? Is that healthy? If this was the only book in the

universe for children about autism, I'd agree with you. But since there are a wealth of other titles unpicking sensory and social challenges – and autistic people are only too well acquainted with what sets them apart – let's make room for one fabulous voice that brashly celebrates diversity. What a fabulous message for any young reader to internalise and carry with them for the rest of their lives.

We have a copy of I Am Utterly Unique to give away to one lucky reader. Just tell us something unique about YOUR CHILD in under 25 words! E-mail your answer to competitions@aukids.co.uk no later than February 29th 2016.

Debby Elley,
 AuKids co-editor



BOOK
I've Got a Stat For You - My Life With Autism

By James Lumsden-Cook
 Published by Bennion Kearny Ltd
 £9.99
 ISBN 9781911121008

When he was diagnosed with severe autism in 1989 aged four, Andrew's mother was told it was likely he would be

institutionalised. However, these memoirs reveal an inspiring man who has secured his dream job and has already led an interesting and fulfilling life. The book is incredibly honest and Andrew shows great self-awareness as he details his progress and triumphs, as well as his low points and how he learnt from them. The book is an easy read and gives a great understanding of Andrew's autism and the impact it has on his behaviour and relationships.

Alison Palmer,
 AuKids' reader panel

WEBSITE
Sesame Street Online Autism Resources

autism.sesamestreet.org

Our two year-old daughter, Yael, was recently diagnosed with autism. As luck would have it, right after we got Yael's diagnosis, Sesame Street introduced a new character called Julia, who is autistic. A whole section of their website at www.sesamestreet.org is now devoted to information about autism; the perfect way to explain autism to Yael's four year-old sister Tamar!

First we looked at the digital storybook where Elmo explains to Abby that he has been friends with Julia for a long time and she does some things differently because she has autism, such as building walls of blocks and spinning the wheels on toy cars and trucks.

Julia doesn't respond to Abby's questions, which makes Abby feel sad, so Elmo explains that Julia just needs a bit more time to respond sometimes. There are also some interesting problem-solving parts of the story, such as when Julia is bothered by the loud blender in Hooper's Store and doesn't want to drink hot cocoa with the others. The storekeeper turns off the blender for her and suggests cold chocolate milk for Julia instead.

The book can be read aloud by a narrator, or you can choose to read it yourself. Tamar really enjoyed the story and made comparisons with Yael as we read it ('Yael builds walls of blocks like that!'). Then, she also decided to diagnose herself with autism, since she doesn't like loud noises either!

Next, we looked at one of the many video stories that are available and watched A Sibling Story, where seven year-old Jazlyn introduces viewers to her younger sister Yesenia, who has autism. The video shows how Jazlyn and her older sister help Yesenia do things that are difficult for her (such as distracting her while their mother brushes her hair), and explains that Yesenia uses sign language to communicate, since she can't speak. Tamar again made comparisons with Yael, who is also non-verbal and uses signs, and it was the perfect way to point out how she can also be a great big sister and help Yael.

The theme used by Sesame Street for this part of its website is See Amazing in All Children, and features the 'Amazing'

song and accompanying video. The site also offers printable daily routine cards to help children get used to experiences like eating in a restaurant, brushing their teeth and going to bed – all featuring familiar Sesame Street characters and using simple, precise language.

The creators really put a lot of research and effort into their site and provide a Read More section, with short articles such as Preparing for Outings and What to Say to a Parent of a Child with Autism. My only quibble is that there is no direct link from the main Homepage – you have to either search specifically for autism or use the drop-down menu to select 'Toolkits' and then choose the 'Sesame Street and Autism' link. Much easier just to type in this address: autism.sesamestreet.org

For our family, the launch of this website was perfect timing and proved to be a very valuable resource. Tamar is very proud to tell people about autism and why her sister Yael does things a little bit differently.

Delia Jarczyn,
 AuKids' readers panel, Canada





TALK
An Afternoon With...Dr Jacqui Jackson and Family
 Hosted by Autistic Intelligence

November 6th 2015. The Boardroom at St James, Manchester.

When Autistic Intelligence was formed, its ethos was to offer down to earth, jargon-free talks from people who lived and breathed autism – and at a reasonable price.

To me, the pinnacle of this dream came with the Afternoon With... sessions in Manchester last year, when parents were invited to hear really well known speakers for an affordable price. No faffing with lengthy preparations and wrangling with childcare. Sit down, listen to brilliant speaker, leave.

Presenters during October and November were Dr Luke Beardon, Elaine Nicholson, Dr Jacqui Jackson and family and Olga Bogdashina. If those names are familiar to you, it's because AuKids often draws on experts who like to speak in an ordinary, non-clinical speak too.

We attended most of these sessions, but it was the first time we'd seen Jacqui Jackson and her fabulous family in action.

The refreshing thing about listening to the Jacksons was that this was a chat, not a presentation. Those expecting an instruction manual on raising autistic children (Jacqui has eight, most of them on the spectrum)

would be sorely disappointed. It was more a series of observations told by Jacqui, and her sons Ben and Luke. Ben is a teenager and Luke, now in his twenties, is the author of Freaks, Geeks and Asperger's Syndrome (which he wrote when he himself was a teenager). Family stories were shared in an engaging and often flippant style, which will be a welcome relief to anyone used to laser pointers and reams of handouts. This is autism as it's lived.

The talk's lack of structure, plus some technical hitches, did mean that the family didn't get through all that they wanted. Nevertheless there were some powerful nuggets of wisdom to pocket.

Endless personal battles, too many to mention here, have been fought and won by this defiant but gentle, self-effacing mum. The family's resilience and resourcefulness in the face of ignorance – much of it experienced in educational settings – is just incredible. What's even more baffling is that they find the time to share their story with others. Catch them if you can.

More Afternoons With...are planned for London this spring. Check www.autisticintelligence.org for details of new events.



Link to the best help and support

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



Make Communication A Picnic With The Talk with Teddies Team!

When communication comes from one of those confusing adults, it's hard to digest, but The Play Doctors, Talk With Teddies kit means that messages can now be communicated in an undemanding and appealing way. Each teddy is made of Velcro-compatible fabric that allows a visual symbol card to be placed on its tummy. The bears can be passed around, cuddled or fiddled with.

Using the teddies can help children understand social rules, make choices and know what's happening next. They can also be used to teach colours, categories and matching – and of course in games or story-telling. They can express an emotion and support a child's own communication, too.

Speech and Language Therapist Kim Mears says that she bought a pack of teddies at the Autism Show. 'Little did I realise how much children would like them and how useful they would be. The other major advantage is that they are well made and have survived

most of the hazards of being handled by children, which is great as not much survives!'

Kim says she's used the bears to teach turn-taking (hold the bear when it's your turn). 'Alternatively, the bear has 'wait' on his chest and the child holding the bear waits while the other child takes their turn,' she says. She's also used the words 'speak' or 'think' on the bears to show whose turn it is to do either of those things.

A Comprehensive Ideas and Information booklet that comes as part of the kit will inspire you to find many activities for the bears and the little hands that hold them!

With each set, you'll receive four bears, 12 printed symbol cards, 6 mini dry wipe boards, a dry wipe pen, communication display board, 5 coloured fabric shapes per set, the Comprehensive Ideas and Information booklet and a robust draw storage string bag.

The Talk with Teddies kit is available for £39.95 (excl. VAT) from www.theplaydoctors.co.uk



Win a Talk With Teddies Kit!

Just hunt for the adorable green bear hiding in this magazine and tell us where he is! Send your answer labelled 'BEARS' in the subject header to competitions@aukids.co.uk no later than February 29th 2016. One lucky winner will be selected at random after the closing date! No cash alternative.

GOOD LUCK!



CONFERENCE
Autism - A Hands on Approach

November 24th 2015. Stepping Hill Hospital, Stockport.

A sold-out conference saw both parents and professionals attending talks that included author Charlotte Moore giving a lively update on her adult sons George and Sam.

Consultant Child Psychologist Phil Christie gave a presentation titled Promoting Emotional Well Being and Demonstrating Outcomes for Children on the Autism Spectrum. In it, the speaker explained his experience of using 'personal tutorials' for school children. Similar to counselling sessions, these help to address social problems early.

Professor Jonathan Green reported on his team's research at Manchester University in a talk titled Progress in Developing Effective Early Interventions for Infancy and the Preschool Years. His group's recent trial using parent-mediated interventions for children between nine and 14 months was described as a potentially 'game changing' approach.

Parent Debbie Walters shared her family's experience as one of the first to change over to the new EHC plans, followed by Dr Sarah Parsons discussing

the use of collaborative technologies to promote social conversation for those on the spectrum. Dr Caroline Richards from the Cerebra Centre for Neurodevelopmental Disorders addressed delegates on her research with Professor Chris Oliver on Self-Injurious Behaviour. Lynne Moxon also gave a presentation titled Sex and Sexuality: Why Are Young People with ASD So Vulnerable?

Afternoon workshops covered subjects including siblings, sensory strategies and supported living and employment. The Sensory Strategies workshop run by Corinna Laurie included ideas for sensory equipment on a budget.

Our reviewers felt that there was scope for delegates to network with each other further and more opportunities for audience participation in general. Helen said that she would have liked more help with practical daily, short-term strategies. Overall, however, the conference was a helpful update on new approaches in autism.

Mark Haworth and Helen Dutt, Time Specialist Support



“ I struggle taking my son to the supermarket. He has a meltdown every time. What can I do? ”



Heather MacKenzie

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

on? Aromas can be off-putting. Noise and crowds can make stores challenging places to be. If there are sensory concerns, try to time your visit to the supermarket so crowds are reduced. See if your child would like ear protectors or his favourite music/soundtrack to listen to while at the supermarket.

At the supermarket: Stay calm or, at least, appear calm. Our children pick up on stress and anxiety. Take a few calming breaths and let old memories of meltdowns fade away. Don't fret about what *might* happen.

If appropriate, be sure to have your child's earphones in place before entering the store.

Let your child take command of the shopping list. You can have him check off items as they're put into the cart or use a Velcro list so he can tear off each item.

Stick to the original plan. Your child expects to head home after shopping.

Debriefing: Get your child to help you bring groceries into the house and put them away. That's part of the process and it's another way your child is helping and getting closure.

Review the plan with your child. Let him know what parts he did well and how he helped you with the shopping. Ask him or give him choices of what might make shopping better for him.

Think about the whole experience. Keep the things that worked well and figure out how to revise parts that didn't work well.

Children with autism need (a) time to warm up to new or changed settings/activities, (b) help focusing on the most important and relevant details (c) logical, objective information about what's going to happen and (d) closure - understanding how they know it's finished.

Preparation: Your child needs to know what's going to happen, why and when. Giving him some choices in this process can add to his willingness to cooperate.

- **Plan:** make a plan with your child so he knows the details (e.g. get in the car, go into the supermarket, select foods, cash out, return home). This gives him time to warm to the activities. Let him have some things to control, like which store to go to, which foods to get. Make sure to tell him you need his help in getting the shopping done.

- **Sensory issues:** Think carefully about when and where he tends to have meltdowns at the supermarket. Could there be sensory things going



THAT'S MORE LIKE IT! The Autism Friendly Fantasy Supermarket



Luke Beardon

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

not knowing what is happening, how long is it happening for and when it is going to end.

By developing some focus and predictability, the experience can sometimes become far more bearable, or even a positive one.

Shopping lists (written or visual) in the order in which items are going to be sought can be really useful, especially if on a whiteboard or tablet, so each item can be deleted once it has been bought.

If the child takes responsibility for the list s/he may feel more in control; additionally, the child will be able to see what progress is being made - and there is a clearer beginning, middle and end.

Supermarkets are notorious examples of being full of sensory activity which may prove seriously difficult to cope with.

For some, it is essentially impossible to access without becoming overloaded. Others, though, may be able to access the supermarket at times when there are fewer distractions, e.g. early morning or late in the evening.

However, it is often not practical for parents to be accessing shopping at quiet times - so it may be the best bet to go for the immensely autism friendly option - shopping via the Internet!

I suspect that there are three main reasons for the meltdowns: issues with predictability; issues with sensory overload and a combination of the two! Whatever the reason, it is critical to take note of the meltdowns - all too often this is a form of communication equivalent to "this is really far too stressful for me, get me out of here" - in which case due consideration should be made in terms of what the purpose of the activity actually is; possible questions to frame include:

- Is my child actually getting anything out of this?
- Is this doing more harm than good?
- What are the consequences - short and long term - of exposure to a highly a stressful situation?

Many autistic individuals get massively stressed when life is unpredictable - and life in general is hugely chaotic for many.

Going to the supermarket may simply be just another example of



Expert Olga Bogdashina gives a personal account of her supermarket experiences... see next page.

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

BLOGDASHINA

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, 26, is the inspiration behind her career.

Over the years, the two of them have developed strategies to cope with the supermarket environment. Avoidance, she says, may be tempting, but in her own son's case, desensitisation helped...

Blog 4

Aisle Be Back!

Why We Never Steered Clear from the Supermarket...

Having trouble supermarket shopping with an autistic youngster? I understand this problem only too well: from the time my son was a toddler, it was impossible to take him shopping with me. Anything (and I do mean ANYTHING) could trigger his meltdown.

Sometimes I could identify the cause of it (even if it took days after the event) – constantly playing the 'video' of the latest catastrophe in my head until I found a more or less rational explanation. My boy was bombarded with noises from all directions, drowned in lights, attacked by smells and disoriented by people moving in chaotic patterns.

To keep him at home with a child-minder while I was shopping or

going out was not an option. In order to integrate him into the community I had to introduce him to the public and provide my boy with as many experiences as possible.

I knew that Alyosha was unable to cope with the demands of an outside world he was not equipped to deal with, so no wonder he was likely to display what we call 'challenging behaviours' when we were in public places.

Knowing that he had no control over his behaviour – they were caused by his 'neurological make-up' – meant that he couldn't adjust to the ever-changing environment without specific help.

The first step was to identify his problems: inability to filter visual and auditory sensory stimuli, leading to hypersensitivities.

The next move was to solve them by either desensitising his vision and hearing (or providing visual and auditory aids) and/or accommodating the environment to his needs.

It doesn't sound too complicated, does it?

In real life, however, it's not that simple. I knew my son could not tolerate fluorescent lights, babies' crying (the high pitch of the baby's screaming was drilling through his ears), and people moving in different directions. What was I to do...go in beforehand demanding all the lights were switched off, whilst escorting all mothers with young children out and ordering the rest to move one by one in a straight line, keeping their voices down? That wasn't exactly an option.

Operation Supermarket was likely to be long-term and needed a lot of planning and organisation. We decided that every Sunday morning we'd go shopping in a big supermarket (the same supermarket at the first stage of the adventure), equipped with tinted glasses and ear-defenders against visual and auditory 'offences'.

Starting with small doses of the shopping experience, we hoped to desensitise my boy's ability to tolerate the stimuli other people were comfortable with.

The first time was the most

successful. However, it was too early to celebrate. Yes, Alyosha did cope with his first visit of the supermarket, but his 'stay' there lasted all of 30 seconds. We went in with a trolley (and determination) yet had to leave pretty soon afterwards. Still, it was a start!

Next week we managed to reach the first aisle and spent nearly two minutes inside. The following weeks, our shopping experience lasted longer and longer and I realised he was finally beginning to get accustomed to the foreign nature of the place and the stimuli.

Fast forward a year: our shopping trips were no problem (not only in this supermarket but at any other shop). Alyosha happily pushed the trolley, zig-zagging along the aisles, correcting 'the wrongs' on his way (picking up misplaced things and putting them where they should be, straightening the rows of tins and cans, etc.)

“**Operation Supermarket was likely to be long-term and needed a lot of planning and organisation.**”

From time to time there were moments when my interference was necessary – for such situations we'd developed a scenario to help him relax and focus on his duties. So, if he heard a baby crying far away from us at the other end of the supermarket, he looked at me and officially announced: 'A baby is crying,' expecting me to say my lines of our pre-approved 'play script'. (This was not the time to develop flexibility).

I always obliged: 'Yes, the baby is crying because it's small and stupid. You are big and clever, so you behave like an adult.' Anyone could see that Alyosha felt much better and was doing his best not to react to the painful sound. But that wasn't the end as I always added, 'When you were a baby you also cried but now you've grown up.'

Has it been always happily ever after? Not quite. For example, to

take him pre-Christmas shopping in an unfamiliar supermarket a few years ago was a big mistake. Our usual shopping 'adventure' turned into a nightmare.



CHECK THIS OUT! A teenage Alyosha had become comfortable in supermarkets

There were THOUSANDS of people in the supermarket, music, sales announcements, babies crying, people talking and moving in all directions, long queues... In 15 minutes I could see that the overload was setting in.

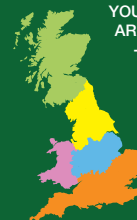
My boy was literally 'attacked'. I could see he was in pain. The last straw was when a lady tried to reach the shelf from behind while we were standing in a queue. Alex lashed out and hit her. I attempted to get him out as soon as possible but all the aisles were blocked by trolleys and people. Those around us were staring (and it did not help as Alyosha could not tolerate any direct perception). While I was dragging him out of the shop, he was kicking the trolleys, pushing people...

Outside my boy was crying, trying to explain: 'It was a panic attack. My eyes hurt. I didn't want to hurt anyone. I won't do it again. I will fight my panic'. I knew he was doing his best and told him that I understand what has happened, that it was not his fault, that I loved him...

Of course, the people around us had no idea why a handsome teenager was screaming like a baby and being aggressive to others...In this way I've learnt not to push it too far. But on the whole, Operation Supermarket has been a huge success.

2016 HIGHLIGHTS

Get the Diary Out!



YOUR AREA'S EVENTS ARE COLOUR CODED - CHECK THIS KEY!

Scotland

North

Midlands

South

Wales

JANUARY

Sun 31st Jan - Mon 1st Feb Now in its second year, the IIC Show in **Manchester** is a super sized trade and consumer event that actively promotes Inclusion, Independence and Choice for people of mixed ability and those associated. For anyone with an interest in the public, political and social aspects of disability. Manchester Central. Register free at www.iicshow.co.uk Pick up a free copy of AuKids here!

Wed 3rd Introduction to Autism, A BILD Learning and Development Day, British Institute of Learning Disabilities, Birmingham Research Park, 97 Vincent Drive, **Edgbaston**, Birmingham B15 2SQ. Tel: 0121 415 6960. This one day programme will provide you with an overview of what autism is and the ways in which it can affect individuals. www.bild.org.uk Cost: £95 + VAT.

Sat 6th Effective Communication, Autism & Asperger's conference, hosted by Autism Oxford at Thames Hall, The Kings Centre, Osney Mead, **Oxford**, OX2 0ES. Featuring author and lecturer Olga Bogdashina, speaking on 'Communication Issues in Autism: Do We Speak the Same Language?' Also featuring Autism Oxford's Autistic Training Team, NAS Professional Award Finalists in 2014 & 2015. Booking rates: Professionals: £75 + VAT; People with ASC & Family Members: £60 + VAT. Concession rate: £45 + VAT. Lunch not included. Group Discount: 20% off for groups of 5 or more professionals. Book at: www.autismoxford.org.uk E-mail info@autismoxford.org.uk

Tues 23rd Learning to Wee and Poo in the Right Place – continence problems in children with autism.

Course hosted by the NAS with community paediatrician Dr Eve Fleming and Lorraine MacAlister of the NAS. Venue: Scope, 6 Market Road, **London**. £185 + VAT. For details look up www.autism.org.uk/training

MARCH

Tues 1st Parents in Partnership (PIPS) Information Day, **Stockport** County Conference Centre, 9.30pm-4pm. Free information day with stands on services throughout the area for all carers of children and young adults with disabilities. For further information, email info@pipstockport.org See AuKids here!

Tues 1st - Wed 2nd The National Autistic Society's Professional Conference. Telford International Centre, **Telford**, UK. The event provides a unique opportunity for professionals from education, health and social health sectors to network, discuss best practice and share learning. Expert speakers will present an overview of the changing environment and the latest developments in the field of autism. There will also be a series of seminars. Book at www.autism.org.uk/professionals/conferences/professionals.aspx

Fri 4th The Big Autism Play Day, **Manchester**. Venue TBA. The Big Autism Play Day focuses on supporting pupils aged roughly 2 to 19 years (all abilities) and might be helpful for parents, foster carers, teachers, learning support assistants, early years practitioners/nursery nurses, play workers, respite/short breaks providers, speech and language therapists, occupational therapists and other autism professionals. Cost: £245 + VAT per place, including lunch. To book go to www.hirstwood.com or for enquiries e-mail lois@hirstwood.com.

Tues 8th Learning to Wee and Poo in the Right Place – continence problems in children with autism. **Birmingham** course hosted by the NAS with community paediatrician Dr Eve Fleming and Lorraine MacAlister of the NAS. Venue: Birmingham City Football Club. £185 + VAT. For details look up www.autism.org.uk/training

Wed 9th Understanding Stress and Anxiety in Autism and their Impact on Behaviour – course hosted by the NAS in **London**. £185 + VAT. For details look up www.autism.org.uk/training

Thurs 10th Kidz in the Middle, 9.30am-4.30pm, Jaguar Exhibition Hall, Ricoh Arena, **Coventry**, CV6 6GE. Free entry, free parking, fully accessible. One of the largest, FREE UK exhibitions dedicated to children and young adults with disabilities and special needs, their families and the professionals who work with them. Over 120 exhibitors offering advice and information on funding, mobility, seating, beds, communication, access, education, toys, transport, style, sensory, sports and leisure and more. Running alongside the event are FREE seminars for parents and professionals. Topics include: moving and handling, sleep issues, continence issues, direct payments, parental experiences, transition and legal advice. www.kidzexhibitions.co.uk or e-mail info@disabledliving.co.uk

Fri 11th The Big Autism Play Day, **Birmingham** (venue TBA). The Big Autism Play Day focuses on supporting pupils aged roughly 2 to 19 years (all abilities). See Manchester description under Friday 4th. Cost: £245 + VAT per place, including lunch. To book go to www.hirstwood.com or for enquiries e-mail lois@hirstwood.com.

Tues 15th Understanding and Supporting Children with PDA. Course delivered by Phil Christie from the Elizabeth Newson Centre. Hosted by the NAS in **Birmingham**. £185 + VAT. For details look up www.autism.org.uk/training

Wed 16th Sensory Considerations – course hosted by the NAS, includes support strategies. **Nottingham**. £185 + VAT. For details look up www.autism.org.uk/training

Fri 18th The Big Autism Play Day, **London** (venue TBA). To book go to www.hirstwood.com or for enquiries email lois@hirstwood.com with your requirements.

APRIL

Sat 2nd WORLD AUTISM AWARENESS DAY! GET YOUR T-SHIRTS ON! (see ad on page 16)

FEBRUARY

Tues 2nd The NAS hosts the Autism and Technology conference at Copthorne Tara Hotel, **London**. This one day conference will feature the latest research and developments in technology for autistic individuals and the professionals who support them. The conference will feature interactive seminars – topics assistive technology, staying safe on the Internet and the power of social media. Speakers include Matthew Goodwin, Dr Laurie Sperry, Mark Brosnan and Juli Crocombe. To find out more go to www.autism.org.uk/news-and-events/nas-conferences/all-conferences/2016/technology/register.aspx

About Autism

talk . experience . learn . enjoy . 2016

Saturday 15th October 2016

The Floral Pavilion, Marine Promenade, New Brighton, Wirral CH45 2JS

10am - 4pm

Information for parents, carers, professionals, and people on the autistic spectrum.



- Speakers include Anna Kennedy OBE and Alex Lowery
- 30+ exhibitors of products, services, and advice
- Free goody bag for all attendees
- Art gallery
- Quiet room
- Cafe
- Free parking
- Fully accessible

www.aboutautism.co.uk

/AboutAutism

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contact@aboutautism.co.uk



Tickets £5, under 16's free

www.floralpavilion.com

Tickets can be purchased through the venue website

Thurs 14th & Fri 15th Autism Oxford presents Professor Tony Attwood and Dr Michelle Garnett at Thames Hall, The Kings Centre, Osney Mead, **Oxford**, OX2 0ES. Day 1: Exploring & Managing Emotions. Day 2: Friendships, Relationships & Sexuality. Professor Tony Attwood is the world renowned author of 'The Complete Guide to Asperger's Syndrome' and his colleague Dr Michelle Garnett is the founder and director of the Minds & Hearts Asperger's Syndrome and Autism Clinic. Also featuring Autism Oxford's autistic training team, NAS Professional Award Finalists in 2014 & 2015. E-mail info@autismoxford.org.uk or look up www.autismoxford.org.uk for details.

Fri 15th Creating An Autism Friendly Hospital conference – Post Graduate Education Centre, Central **Manchester** Foundation NHS Trust. Email frances.binns@cmft.nhs.uk or call 0161 701 5504. See AuKids here!

Weds 27th ChAPS Autism Specific exhibition, Frodsham Leisure Centre, **Cheshire**, 10am-5pm, for details: www.eventbrite.co.uk/e/chaps-exhibition-tickets-20777294447 See AuKids here!

Fri 29th - Sat 30th NASEN Live, Royal Armouries, **Leeds**. Caters for anyone working in the field of special and additional educational needs and disability, including leaders and headteachers, SENCOs, class teachers, support staff and local authority staff. www.nasen.org.uk

MAY

Thurs 26th The Transition Event, The National Motorcycle Museum, **Birmingham**. Building the best future for young people with additional needs. This annual, one day conference and exhibition explores the essential aspects of a young person's transition to adulthood when they have additional needs. For information, contact Cheryl Yardley on 01223 206953 or e-mail cheryl.yardley@carechoices.co.uk

JUNE

Thurs 9th Kidz to Adultz South exhibition, 9.30am-4.30pm, Rivermead Leisure Complex,

Richfield Avenue, **Reading**, RG1 8EQ. Go to www.disabledliving.co.uk/kidz for details. Free entry.

Thurs 16th Towards A Positive Future, for parents of children with special educational needs and the professionals who support them. Riverbank House, 2 Swan Lane, **London**, United Kingdom, EC4R 3BF. Go to www.senconference.co.uk or call 0333 123 8895.

Fri 17th - Sat 18th The Autism Show, ExCel, **London**. The Autism Show is the national event for autism (including Asperger Syndrome), dedicated to the two million people in the UK who live and work with the condition on a daily basis.

This year's Autism Show in London, Birmingham and Manchester offers more information, advice, products and services than ever before.

At the event you can hear from the UK's leading autism professionals, discover hundreds of products and services, learn practical strategies for the home and classroom, listen to adults on the spectrum talk about their experiences, access specialist advice from clinicians, therapists and solicitors, and take part in new special features such as the Sensory Classroom and the Get Cycling Test Track. Look up www.autismshow.co.uk for details.

Fri 24th - Sat 25th The Autism Show, NEC, **Birmingham**. See above for details or look up www.autismshow.co.uk

JULY

Fri 1st - Sat 2nd The Autism Show, EventCity, **Manchester**. As above. www.autismshow.co.uk

Thurs 7th Kidz to Adultz Wales, National Indoor Athletics Centre, **Cardiff**. New for 2016! Over 100 exhibitors and free seminar programme. For FREE visitors' tickets and to register your interest call 0161 607 8200, e-mail info@disabledliving.co.uk or look up www.kidzexhibitions.co.uk

AUGUST

Tues 16th - Fri 19th Autscape conference, organised by and for autistic people, Giggleswick School, **Yorkshire**. Non-autistic people are also welcome, but the environment and content are centred on autistic people's needs, interests and sensitivities. Autscape includes workshops, leisure activities, social opportunities, and more. Look up www.autscape.org



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in the North of England

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www.iicshow.co.uk
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FREE ENTRY

SEPTEMBER

Thurs 15th Kidz Scotland, Royal Highland Exhibition Centre, **Edinburgh** EH28 8NB. Free disability event heads to Scotland for the first time. Go to www.disabledliving.co.uk/kidz for details or for tickets e-mail info@disabledliving.co.uk

OCTOBER

Fri 7th - Sat 8th TES Events presents TESSEN show, Business Design Centre, Islington, **London**. This important free-to-attend event has all the resources, ideas, advice and CPD training to provide teachers, SENCOs, support staff and parents with the tools and skills to help all pupils achieve. Go to www.tessenshow.co.uk to pre-register.

Sat 15th About Autism, 10am-4pm at The Floral Pavilion, Marine Promenade, New Brighton, **Wirral**, Merseyside CH45 2JS. Centred on the sea front next to New Brighton's regeneration project, the Floral Pavilion is a state-of-the-art conference centre, which is fully accessible and central to bus and train services, with plenty of parking options. Exhibitors will include local schools, sensory products,

magazines, charities, technology, and health services. There will be talks in the adjacent theatre, a quiet room will be available and the on site café will provide refreshments. www.aboutautism.co.uk See AuKids here!

NOVEMBER

Tues 15th 13th National Autism Hands-on Approach conference, Stepping Hill Hospital, **Stockport**, Cheshire. Follow on @autism_handson (Twitter) or contact Tanya Farley 0966 399709. Top flight professionals give talks and host workshops.

Thurs 17th Kidz to Adultz Up North free exhibition, EventCity, Barton Dock Road, **Manchester**, M17 8AS. Another freebie run by www.disabledliving.co.uk, the largest they do.

For Autism Oxford events, which take place throughout the year, go to www.autismoxford.org.uk/index.php/events.

The NAS Earlybird course is for parents whose children have received a diagnosis of ASD and are pre-school age. They take place throughout the country. Call 01226 779218 or e-mail earlybird@nas.org.uk for more.

Autistic Intelligence also hosts events throughout the year; their first took place before AuKids went to press. Go to www.autisticintelligence.org/1/conferences



The Great Pretenders

How Autistic Girls Fooled the World

Current statistics would have us believe that only one in five people on the autism spectrum is female. Lately, however, a new theory has emerged. If assessments for autism have been designed around autistic traits typical in males, then guess what? More males will be diagnosed with autism. So what's the real story? Read on...

We could well be heading for an era when the numbers of girls diagnosed with autism undergoes a steep rise. That's not because girls are suddenly developing the condition; it's because there's a growing feeling that until now they've fallen under the radar in a big way.

According to a National Autistic Society survey, just 20% of girls with Asperger Syndrome or high functioning autism have been diagnosed by the age of 11, compared with 50% of boys. So even when they do have a diagnosis, it appears to be happening a lot later.

In his article *The Gender Gap in Autism: Where Are The Girls?* researcher Dr Lee Wilkinson agrees that 'over reliance on the male model' of autism might be part of the reason behind girls being diagnosed much later, or not at all.

There are other factors behind a lack of diagnosis, though. Dr Wilkinson, author of the award-winning *A Best Practice Guide to Assessment and Intervention for Autism and Asperger Syndrome in Schools*, points to the fact that boys with autism often have more unusual visual interests and lower levels of appropriate play than girls with the condition. As a result, he says, their needs are difficult to ignore.

There's another reason, though, why girls aren't spotted sooner. It turns out that they are masters of disguising their social difficulties. Delayed speech and rigid thinking may well be as obvious in girls as it is in boys. But when it comes to social behaviour and imaginative play, girls tend to mirror what they've observed in others. And it seems as though they've been doing a very convincing job of it.

The huge personal cost of this brings us to another reason for girls not being diagnosed with autism; they are often being given other labels, instead. The endless pretence to appear 'normal' can be so stressful that secondary problems tend to take centre stage - social anxiety disorder, obsessive compulsive disorder and generalised

anxiety disorder to name but a handful.

If we're to help girls with autism, we've got to recognise this accomplished acting for what it is. Jennifer Cook O' Toole's groundbreaking book 'Sisterhood of the Spectrum' includes what she calls a *chicklist checklist* for girls with autism. Here, she shows parents and teachers how to watch for underlying difficulties beneath a 'socially acceptable' veneer.

According to Jennifer, this is what we should be watching for:

DIGGING DEEP: The interests that girls on the spectrum have are often similar to others. It's the level of intensity, rather than the subject matter, that sets them apart.

BUBBLY DISGUISE: Being overly bubbly and magnanimous is a common (yet exhausting) way many girls on the spectrum camouflage their social anxiety. Look beyond the surface.

NOT SO SPONTANEOUS: Parents or teachers may see girls playing 'typically' with dolls or dress-up clothing. A closer look will usually reveal play scenarios that are restrictive to strict, special-interest-driven scripts (i.e. Barbie dolls who are actually re-enacting Greek myths or news events).

SETTING SCENES: Girls' play may involve setting precise tableaux - a dollhouse scene, barn replica or Barbie wedding, for instance -

rather than engaging in spontaneous, interactive play.

THE HIDDEN LINE-UP: Lining up figurine collections (Smurfs, dolls, all of the books in a series) looks less conspicuously spectrum-ish than boys' rows of toy cars or trains, but the behaviour is the same.

PARALLEL WORLDS: Dictionaries for futuristic alien societies. Wiki boards all about hairstyles and social strata from a specific time period. These are all 'worlds' where girls can imagine themselves succeeding - worlds with fixed, clear, customs, clothing and languages that leave a whole lot less room for mistakes.

FASHIONABLE FAÇADE: Looking or sounding fashionable is as common among girls on the spectrum as is disinterest in appearance. Girls on the spectrum are frequently fantastic mimics (often boosted by a love of theatre), can echo accents perfectly, and work tirelessly to assemble what they see as a desirable persona or façade.

SOCIAL SPECTATORS: Girls' special interests can transport them to a distant time, place, species, or social scenario where interpersonal rules and customs can be studied and mastered. Spectrum girls have a tendency to gather and memorize as much information as they can on social roles and sexual expectations. It's their way of compensating for what others pick up naturally — and it can be very dangerous.

PEOPLE PATTERNS: Girls often collect information on people and cultures rather than on things, which is why the 'lists' they like to accumulate tend to include family trees/genealogy, timelines, language/translations and maps.

UNBALANCED FRIENDSHIPS: Girls often hyper-focus on having one, all-encompassing 'best' friend. Later, this may evolve to an all-or-nothing self concept of being in or being able to keep a dating partner/spouse, at any cost. Be on the lookout for diminished depth or lack of reciprocity.

TAKING CHARGE: Girls will often take on the role of the 'boss' of younger, needier or new kids - or of a precocious 'little sister'. That's because peer-to-peer collaboration is MUCH harder. Look for phases of intense friendships with break-ups or sudden ends. Being able to establish friendships is very different from being able to maintain them.

BRAGGY BOOTS? Girls with autism can come across (unintentionally!) as braggadocios or know-it-alls and frequently see compliments to others as insults to themselves. This reflects challenges with perspective-taking and low self-esteem, not arrogance.

EATING DISORDERS: Eating disorders like anorexia nervosa and bulimia are very common in women with autism. They're indicators of perfectionist tendencies, internalized self-punishment, a need for artificial control, extreme rigidity and adherence.



AIMEE

AIMEE is 12, lives in Manchester and has autism. Her mum Dawn says: 'The boys love that she likes the things they do, she likes Pokémon, gaming and Anime. She says she will never wear make-up and likes rock and metal music, not boy bands. Her male friends are very protective of her. She's a very lucky girl!'

CHECK THEIR UNDERSTANDING:

Since girls are better at pretending to know what you're talking about just to try and fit in, you may have to be extra careful to check. Girls often learn exactly what to say and what's appropriate to say - and can carry out conversation to a great social level, but without truly understanding the exchange. If they are asked something they haven't prepared for, they are unable to answer.

Alis Rowe.

Don't Let Them Be Miss-Understood

Alis Rowe, who has Asperger's and is the brains behind The Curly Hair Project, and Dr Laura Cockburn, specialist psychologist at the NAS's Lorna Wing Centre, gave AuKids some great tips on bringing up girls with autism.

APPRECIATE YOUR GIRLS!

Their strengths and interests may seem very different to others but they can be very good to build on as the girls get older. Their interests may not seem to be typical for girls and they may prefer what are typically seen to be boys' interests - this is fine!

Dr Laura Cockburn.

Alis says...

MAKE IT OBVIOUS

What may be very obvious and clear to others is often ambiguous and unclear to people on the spectrum. They have a desire to know *why* and won't understand what is obvious or automatic to others.

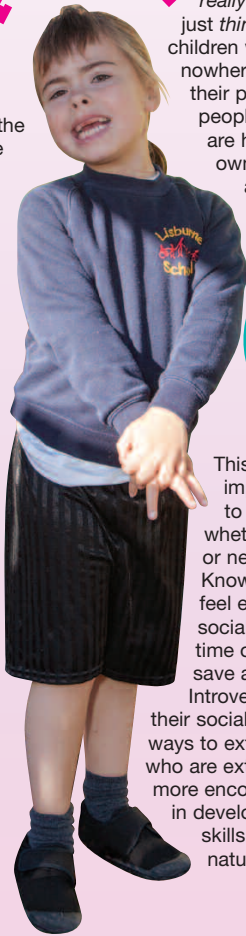
SAY WHAT YOU MEAN, MEAN WHAT YOU SAY

It is important to be straightforward in your communication and try to stay true to your word. For example, if you say 'I'll be back in five minutes,' do you really mean five minutes, or do you mean ten, eleven - or even more? It might seem hard work to alter your language at first but you will get used to it. It is not difficult to say, 'I'll be back between five and fifteen minutes' instead.

ENCOURAGE - BUT DON'T FORCE SOCIALISING

Parents often worry that their child is lacking social skills or that their child is missing out by not having friends. The pressure to

PHOEBE



be social is even greater with girls. Is your child *really* lonely? Or do you just *think* they are? Often, children with autism are nowhere near as lonely as their parents think. Many people on the spectrum are happiest in their own company and alone time is very important to them.

IS YOUR CHILD AN INTROVERT OR AN EXTROVERT?

This is incredibly important for anybody to know, no matter whether they are autistic or neurotypical! Knowing whether you feel energised through socialising or through time on your own can save a lot of daily stress. Introverts need to organise their social lives in different ways to extroverts. Children who are extroverts may need more encouragement and help in developing their social skills than those who are naturally introverted.

PREPARE FOR PUBERTY EARLY

Children seem to be starting puberty earlier and earlier. Where girls on the spectrum are concerned, there is not really such a thing as too soon to start talking about what happens during puberty. Your daughter will typically require more time than her neurotypical peers to process and understand the changes that occur during puberty.

HELP YOUR CHILD TO FIND THEIR SPECIAL INTEREST

Compared with boys, the special interests of girls do not tend to be as eccentric or 'odd'. Tony Attwood has observed that the special interests of girls tend to fit with that of their peers. Observe your child when they are doing the thing they enjoy most - and talk to them about it! What is it about animals or reading that she particularly likes? It will all be in the detail! Finding this interest and encouraging it is key to maximising your child's potential and making them happy. Special interests can be a real comfort during unhappy times that are common in the teenage years.

TALK ABOUT WHAT IT MEANS TO BE 'DIFFERENT' IN A POSITIVE WAY

This is also important for boys, but your daughter, surrounded by gaggles of giggling peers, could be super aware that she doesn't 'fit in'. Telling her that it's the

differences which make us interesting or innovative can help her to value herself. Stress the advantages of thinking differently.

Laura says...

USE YOUR KNOWLEDGE

As girls often don't present with 'typical' patterns of behaviour and communication for autism, they are often misunderstood. Help teachers and diagnosticians to fully understand them. It's often the detail that can help the process of being diagnosed, so don't hold back.

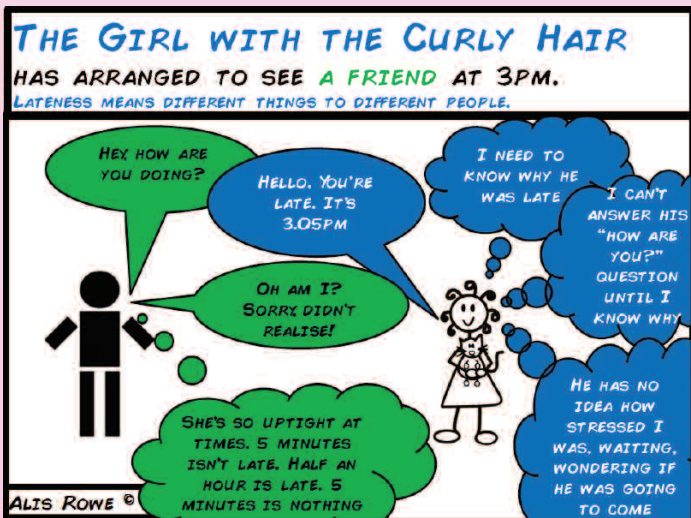
SPOT ANXIETY

Be aware that anxiety is likely to be a big issue and it may not be obvious; it may present in different ways. Be a detective and try to determine causes of anxiety and worry. Work together with your daughter and others to look for ways of reducing anxiety.

LOOK AT BOOKS AND BLOGS BY OTHER WOMEN

More and more autistic women and girls are sharing their experiences with others. This can be really encouraging. No two people with autism are the same, let alone two women, so the more experiences you can read about, the better.

OLIVIA



Continued...

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Sisterhood of the Spectrum - An Asperger Girls' Guide to Life

By Jennifer Cook O'Toole
Published by JKP • £13.99
ISBN 9781849057905

On its publication, this handbook for girls and women on the spectrum was for many the book they'd been waiting for. Here, author Jennifer Cook O'Toole shares her own experiences as a woman on the spectrum and has used each memory (which she relates with zingy humour and brash honesty) to illustrate the pain and pitfalls of being misunderstood as a girl and later as a young woman. 'Learn from my mistakes,' is the message. Having learnt from them herself, big time, she gives her readers a shortcut.

Her captivating series of stories have been cherry-picked to illustrate common difficulties experienced by spectrum girls. Jennifer's handbook shows her readers everything they need to know to shore up their own confidence, social awareness and personal resilience.

This is a sustaining package that teaches girls how to gain in-depth self-knowledge and gives them an awareness of the agendas of others. The author's buddy-like tone is really engaging; she's the wise big sister you'll keep returning to for advice and support.

This truly is The Holy Grail for girls on the spectrum.

By Debby Elley

WIN!

A Copy of Sisterhood of the Spectrum

Simply e-mail your name and address to competitions@aukids.co.uk no later than February 29th 2016. Put 'Sisterhood' in the subject header. Winners selected at random.

Other Recommended Reading

- I'm An Aspie Girl – A Book for Young Girls with Autism Spectrum Conditions by Danuta Bulhak-Paterson, published by JKP
- What's Happening to Ellie? A book about puberty for girls and young women with autism and related conditions by Kate E Reynolds, published by JKP.
- The Growing up Guide for Girls - What Girls on the Autism Spectrum Need to Know! by Davida Hartman, published by JKP
- Life on the Autism Spectrum: A Guide for Girls and Women by Karen McKibbin, published by JKP
- Women and Girls with Autism Spectrum Disorder by Sarah Hendrickx, published by JKP
- Aspergirls – Empowering Females with Asperger Syndrome – by Rudi Simone, published by JKP
- Pretending to be Normal by Liane Holliday Willey, published by JKP

MAYA



WORLD AUTISM AWARENESS WEEK

The National Autistic Society

World Autism Awareness Week is a fantastic opportunity to raise awareness about what it's like to be a family living with autism. Join in, fundraise and help increase understanding about autism from **Saturday 2 – Friday 8 April 2016**.

www.autism.org.uk/WAAW

Heidi and her autistic son raised awareness in 2015 and loved it – join us this year!

The National Autistic Society is a charity registered in England and Wales (269426) and in Scotland (SC039427).

MANCHESTER
1824
The University of Manchester

Take Part in New Research

The University of Manchester is undertaking some research on language and communication differences between boys and girls on the autism spectrum.

Would you like to take part? If your child is diagnosed with autism, Asperger Syndrome or PDD-NOS and was born between 1st September 2005 and 31st August 2007, you may be able to help us.

We are looking for children who attend mainstream school, have English as a first language and have no other conditions that may impact on their language development.

All findings of the child's language assessments can be shared with the family.

If you'd like to find out more, contact PhD student Alexandra Sturrock at the School of Psychological Sciences at alexandra.sturrock@postgrad.manchester.ac.uk

If You're Happy and You Know It, Draw A Face!

"That was a dis-arrrrrs-terrrrrr!"

Nope, it's not Craig Revel Horwood talking about Carol Kirkwood's Rumba, it's your autistic child's uncanny ability to catastrophize even the smallest event.

Tiny calamities hit us daily. They're like small meteorites bouncing off us. They're annoying but they don't steer us off course.

Autistic children aren't as resilient, though. It doesn't take much, does it, for them to write off an entire day based on one tiny and slightly negative experience? Our kids can lack the ability to assess a situation objectively, put it into context and get it into perspective. Here's where they desperately need our help.

Fear, worry and anger are curious things; they're as big as you want to make them. To help your child cut them down to a realistic size, you need some tools. One very simple tool that can be used with all ages and abilities is a mood diary.

You will need: a blank diary. That's it.

For the school day, you can use a mood diary for each lesson and for break times. The teacher simply asks the child to rate them each with a happy, neutral or sad face. Send the book home at the end of each day. Or, if the child is older, they can fill it in at home after each day next to each lesson title.

Bingo, as an adult you've got an immediate temperature gauge. For the child, they can see in a very concrete way that although they may feel that they've had a 'bad' day, it may have been only a small proportion of it that didn't go well. Help them to focus on the things that went well by looking at the happy faces, because if their responses weren't as strong for the good stuff, it may be harder for them to recall.

Later, when they're ready talk about the things that went not so well, you can both think about how we could 'turn that into a happy face'.

The beauty of this idea is its simplicity. As no major analysis is required, children are usually happy to comply with drawing a face. At the end of the day, count up the happy faces or the more mathematically minded can even derive great satisfaction from saying that 75% of the day actually went really well: undeniable proof that perspective can be slightly awry.

A week to view diary is particularly handy. This allows you to look at general moods over a longer period. As autistic kids tend to focus on small things that they don't like much, it may surprise them to see how much enjoyment they're getting out of their day. The sad faces start to look more in proportion and become more manageable.

What if there are a lot of sad faces?

If a child is often distressed, it's helpful to know what aspects of their environment are making them that way. It's also good to help them rate how upset they are. Introduce a traffic light system of sad face sub-categories – from mildly peeved to really upset. Get them to label the face to say whether it's anger or fear (if they know).

When they're calm, talk about their thinking – why have they given that part of the day that particular rating? Is there a pattern? This will help you get to the bottom of it. For kids who find it hard to pinpoint why they're feeling like they do, this can really help, as patterns are easy to spot.

For children who are non-verbal, a happy or sad choice is a great one to give. It helps them to tune into their feelings and shows them that you acknowledge and care about their responses to their experiences – and that they can affect what happens to them. For those children, it's important that you ask them either during or right after the task and you may need a picture symbol to show them what the question relates to.

CASE STUDY 1

TIM



We introduced a mood diary for Tim at our office to help him summarise his week. At first, his weeks always seemed fairly negative, usually because of one upsetting moment in his other job. Gradually, his assessment of the past week was far more balanced. He says that the diary prevented him from reaching emotional overload. "Instead of the 'bad week' feeling building up, I could just draw the sad or confused face, write down next to it why I felt like that and then I wouldn't feel as bad. I'd look at all my happy faces for that week (sometimes I put why, like I would be meeting a friend) and it would make me feel better as I could focus more on them."

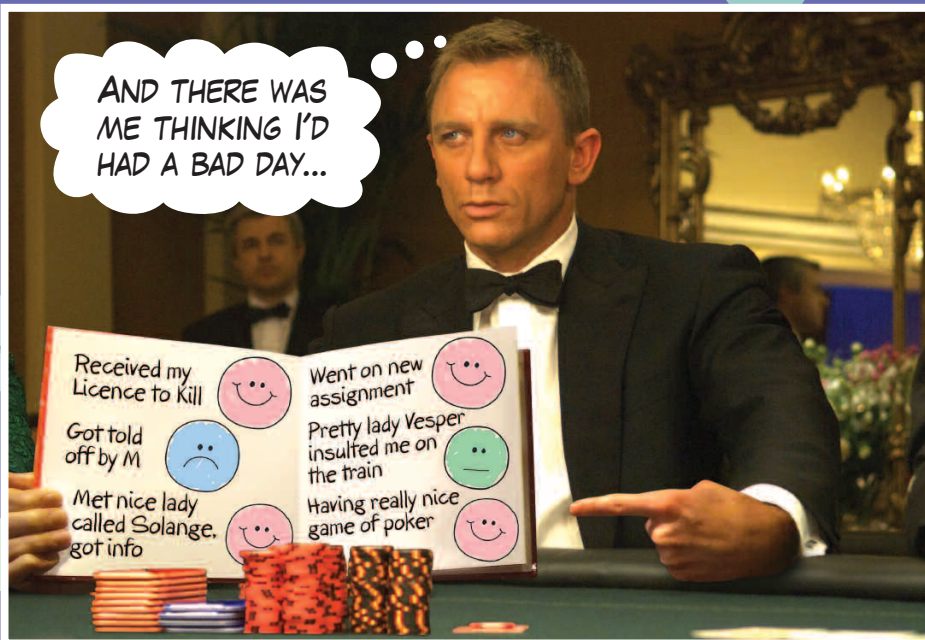
CASE STUDY 2

BOBBY



At school, Bobby's mood diary helps him and his mum keep tabs on how secondary life is going. "We do a verbal happy/neutral/sad face count immediately after school so it's a quick sum up without detail," says his mum, AuKids co-editor Debby. "I immediately know how his day has gone and I promise him that I won't talk about it until later. He doesn't have to go into it when he's tired. Then before bed, when he's relaxed, the faces are talked about in greater detail. It's a great way of zoning in on problem areas. We also dwell on the amount of happy faces to underline how well he's doing."

AND THERE WAS ME THINKING I'D HAD A BAD DAY...



PS. Parents can use mood diaries, too, to help them get problems in perspective!

‘Just the Way You Are..’

Author and speaker Sharon King has three children - Rosie, 17, Daisy, 15 and Lenny, 13. Rosie and Lenny are both on the autism spectrum and Daisy has learning disabilities caused by a rare condition called Kabuki Syndrome.

Sharon's first book 'The Daily Journal of Arabella Crumblestone', a fairy story in which her children appeared as mythical creatures, was published in 2009 and illustrated by her daughter, Rosie. Her second collection of fictional tales, 'The Unfinished Stories' was published the following year. Rosie is well known for presenting Newsround Extra's award-winning 'My Autism and Me' four years ago. Alongside her mum, she is now a public speaker and her positive talk delighted the audience at Manchester's Autech conference last year, organised by Autism Together. She agreed to share some of her thoughts with AuKids.

I couldn't be any more proud of my family.

Rosie, my eldest at 17, has already done so much work on a global scale to raise awareness of autism. She has won a Royal Television Society Award, an International Emmy, been nominated twice for a BAFTA and was given a standing ovation at the Kennedy Center in Washington DC for the TED corporation. She has Asperger Syndrome with severe social anxieties, so has had to overcome so many of her own personal challenges in order to accomplish these considerable achievements.

My middle daughter Daisy is 15 and was born with a rare genetic condition called Kabuki Syndrome. She has a learning age of approximately 18 months, is non-verbal and requires frequent medical intervention. Yet still she achieves every day.

Daisy defied experts' predictions by learning to walk around the time of her fifth birthday. She constantly finds new ways every day of communicating her desires and her emotions, using objects of reference*, gesture and sound.

With her long golden curls and her china blue eyes she is stunningly beautiful and her sunny disposition wins her friends (and affords us unbelievable tolerance) everywhere we go.

‘I've never pitied my children. I feel that they are perfect just as they are, and the only change necessary is the attitude of people around them.’

To think that a cold-hearted paediatrician inscribed the cruel words 'funny looking child' onto her medical notes when she was a baby. Needless to say, we took steps to have this phrase officially removed.

My youngest child is Lenny. At thirteen he is a whirlwind of energy, causing tornado-like chaos and destruction. He is classically autistic and classed as being non-verbal like his sister, although he does use a handful of single words and quite a lot of echolalic language.

Lenny is extremely sensory. He loves the outdoors and constantly strives to stay one step ahead of our ever-evolving security measures and escape from the confines of the house. A typically developing boy with Lenny's interests would spend every evening doing cross country running, fishing, cycling or team sports. However, Lenny's completely cavalier attitude to personal safety means that he must have an adult constantly nearby. How frustrated he must be by this state of affairs I can only guess, but somehow he manages to maintain a largely sunny disposition, singing away in his gruff teenage voice to anything from Bob the Builder to The Fratellis.

Daisy and Lenny are Rosie's inspiration for the work that she does. She worries for their future, for the level of tolerance in the society that they will be part of when their parents are no longer around. This deep concern has given her the courage to make a giant leap beyond what she could have seen as her natural limitations.

I've never pitied my children. I've

made many mistakes over the years, but this is one thing I instinctively got right from the word go. I feel that they are perfect just as they are, and the only change necessary is in the attitude of people around them. Whatever we choose to bathe in attention will grow, so why would I ever pay attention to what I am told my children lack? I have always focused on their strengths and talents and I know that my parenting style has helped them in many ways.

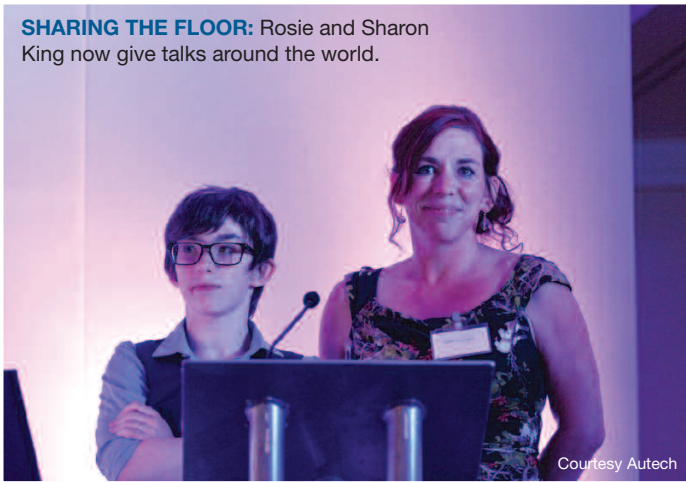
When Rosie was a little girl, I told her that her Asperger's was a superpower. She believed it, and I did, too. I still do. I wrote many stories, placing my children at the heart of them,

turning them into fairies, pirates, heroes. I used their real characters and traits - looking back now I see that I was weaving a spell of words for Rosie, as spell of positivity that worked for us both.

This was all well and good for Rosie, with her natural affinity with language, but what about my other two, non-verbal



SHARING THE FLOOR: Rosie and Sharon King now give talks around the world.



Courtesy Autech

“For all their inability to learn, my children instinctively know that it is experiences, not things, which have true value.”

children? How could I help them with the positivity that I felt?

I studied communication, reading everything that I could, and was relieved to discover that words are only the tip of a

vast iceberg of interactions, with a mass of other ways of

communicating lying silently beneath.

Daisy and Lenny spoke a language of facial expressions, gesture, behaviour and body language – they were communicating with me! And it wasn't a language that I would have to laboriously learn, it is an innate language that we all use, I only had to re-attune to its nuances.

Furthermore, I learned that one of the reasons that words came into being was to *disguise* our true feelings. Words were duplicitous and unreliable. The deeper language that my

children used could only ever be frank and open. I fell even more deeply in love with them.

It often seems to me that my children live through their senses, in the present moment,

exactly as nature intended us to live before we as a race and as individuals were hijacked by the manipulative shadow of our egos.

People with autism have got so much right, and neurotypicals could learn a lot from them. Daisy and Lenny (and Rosie too, to a large extent) place no value on things that they cannot eat, sprinkle, or roll around in.

Piles of toys are litter to them - things to be climbed over, crushed underfoot and discarded. Christmas and birthdays used to make me feel quite uncomfortable, before I adjusted my expectations to suit my children's wants and needs. Every aspect of our society tells us that a good mother provides *things* for her children.

My kids do not want things at all. Music is a favourite in our household, but for its own sake, not because of any pride in the gadget that delivers it. And the best music of all? When we are all singing along, playing Hokey Cokey or dancing in the living room. Priceless things. For all their inability to learn, my children instinctively know that it is experiences, not things, which have true value.

“Sometimes, I am left thinking why aren't we all out here, chasing the leaves?”

It takes most of us many decades to work this out, even for some the realisation comes in the final hours of life. But my learning disabled children have always 'just known'.

Daisy and Lenny inhabit a sensory world that I had rejected, or forgotten, before they came along. Running their hands through dry sand or uncooked rice is an activity that can engage them for hours on end. Patterns engross Daisy. She is fascinated by offcuts of material especially if they are decorated with glittery threads or sequins. She spreads these scraps of material around her as she sits on

the floor, turning to examine them from different angles, arranging and re-arranging her priceless treasures: a true artist who has never picked up a pencil.

A windy day where leaves are chased around in whirlpools of frantic air delights my children. Sometimes, I am left thinking *why aren't we all out here, chasing the leaves?* It's easy to get sucked into the common notion that indoors is safe, warm and comfortable. But our indoor worlds seem so stale in comparison with the other side of the door, where the beauty of an ever changing sky - a moving painting with natural soundtrack and smells and textures - remains uncharted and unchecked.

My ambition for change in our society is that we think twice about dragging our autistic children kicking and screaming into our neurotypical world. That we at least pledge to meet them half way, and that we have the wisdom to take a few steps towards their true, uninhibited, sensory world.

*Objects of reference – an object that represents another e.g. a cup to indicate a drink.



The Daily Journal of Arabella Crumblestone is available for £5 from Sharon King books at www.sharonkingbooks.co.uk/book.htm

The Unfinished Stories priced £6 are available from the same website. £1 from every book sold is donated to the National Autistic Society.





The Last Word

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

Just Give Me a Reason

“Never assume it’s obvious,” was one of the most helpful pieces of advice I ever heard, in a talk by Ros Blackburn some years ago. In both home and school life, this has proved to be an invaluable suggestion. Despite Bobby’s academic intelligence, he lacks an innate sense of the purpose behind the tasks others ask him to do – the bigger picture. This isn’t him being daft, this is autism.

Traditional presentation training for business executives tells us to convey information like this: Tell them what you’re going to tell them. Tell them. Then tell them you’ve told them. This is actually pretty sound advice for getting something across to autistic people, too. Except in their case you really need to add WHY.

Whilst flicking through Bobby’s Beliefs and Values school book the other day, I noticed that he’d written a letter to Malala Yousafzai, who you will remember was shot by the Taliban in 2012 after speaking out in favour of education for women in Pakistan. She was awarded the Nobel Peace Prize in 2014 for her work for children’s rights and now lives in Birmingham.

Now you’d think it would be pretty obvious that if there was anyone on this planet worthy of inspiring young minds to write a letter, it would be her. Wouldn’t it? Apparently not to Bobby.

His letter began... ‘I’m writing you this letter because basically school asked me to...’

Not the most stirring of opening sentiments. But he wasn’t trying to be rude. He was just being honest. He couldn’t see the bigger picture. Plus of course, he’d struggle with this any way because socially it’s hard enough to write someone a

letter particularly when you’ve not got much common ground. If she was into Five Nights at Freddy’s it would be a different story.

I explained to Bobby that the point of writing letters that you’re never going to send is to get in touch with what you have learnt and how it makes you feel.

Why would he know that?

Why would anyone, come to think of it, but the rest of us tend to go with the flow and do what’s asked of us because it doesn’t pose any particular difficulty or threat. With autistic kids, so much of what you ask them *does* pose a difficulty – knowing WHY makes it all so much easier. They need answers far more than most.

At home, I’ve found it a great rule of thumb to explain **why** before I’m even asked to. It just comes as part and parcel of the request, which always has a ‘because’. For instance, today it’s ‘please do your homework this morning and get it out the way, because then we will have some time spare to see Tori’s baby in the afternoon.’

Why, for instance, is he required to do things for himself? Because we’re building up slowly to the day he becomes a millionaire You Tuber (his words) and can also cook cheese on toast to keep him going...

So amend that presentation style and you’ve got the perfect recipe. Tell them what you’re going to do – and why. Tell them - and why. Then tell them you’ve told them – and why.

You’ll know when you’ve changed your style, as the word ‘because’ will be liberally scattered into the air on a daily basis. Yes, it takes a bit longer. Call it an investment.

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



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