



Aukids

Issue 39
Spring 2018

£16 annually
Available from
www.aukids.co.uk

For Parents and Carers of Children with Autism Spectrum Conditions

Sassy Sibs

Brothers and sisters share their stories



What a Howler!
Expert advice on a fear of dogs



Big School Beckons
Top tips to prepare you

PLUS

WIN A light up drawing board and a signed copy of our co-editor's new book, plus other great prizes.



Letter from the Editors

Debby

Tori



It's Spring!

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**

Oh Lordy Lord we can't believe it – AuKids is going to be ten years old in July! Well we can actually, we've got the wrinkles to prove it.

We'd like to celebrate by printing your letters about your favourite AuKids articles in our next issue. Have any made a big difference to you or your family? Please write and tell us at editors@aukids.co.uk. Your letter may be published so do include contact details and photos are always welcome.

This June, the AuKids team will be excited to meet you at the Autism Show in Manchester (we are stand B19). It runs from June 29-30 at EventCity so please come and see us and bring your lovely children. A little hint – it tends to get quieter from 2pm onwards. At our stand, you can sign up for the magazine and also buy a copy of co-editor Debby's new book 15 Things They Forgot To Tell You About Autism – she'll be there to sign it for you.

This spring we've had some lovely input by lots of great advisors. Tim Tuff uses our Inside Angle column to give a rare insight into shutdowns, which are mentioned far less than meltdowns but have an equally distressing effect on people experiencing them. Family Fund expert Jenny Laycock tells you how to get the best from your child's iPad and there's some

great practical advice for those parents whose kids are nervous of other people's pets.

Best of all, we interviewed a group of siblings of all ages about life with an autistic brother or sister. Their wise comments made us wish that everyone could listen to what they have to say. We hope you'll enjoy it.

As usual, we've rounded up some of the best books on the autism market and bagged some great prizes for you - and you won't want to miss our Rule of Thumb feature about making social skills easier to learn.

Keep sending in your letters and pictures, we love to hear from you.

See you for our tenth birthday issue!

Tori & Debby

COMPETITION WINNERS FROM ISSUE 38:

Tony Attwood book: Jo-Anna Dem, Reading; Nicola Naylor, Warwickshire and Lee Guard, High Peak.

Diagnosis book: Sarah Golding, Nottingham and Joanne Sampson, Bristol.

THE NATIONAL EVENT FOR AUTISM IS RETURNING TO MANCHESTER

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WHAT'S IN A NAME?

Orchids are beautiful plants which, much like kids with autism, require very specific conditions to grow. If they get them, they thrive. That's why we called this magazine AuKids. AU is also the chemical symbol for gold.

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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www.periscopestudios.co.uk

autism together

Launches Future 50 Campaign



Chief Executive of Autism Together, Robin Bush

Last month, AuKids attended the launch of Autism Together's **Future 50** campaign in Liverpool. Founded in 1968, Autism Together employs 1,000 people in the North West region and has 19 residential homes. Celebrating its first 50 years, Autism Together's aim behind **Future 50** is to raise funds for a £2.5 million Assessment and Diagnostic Centre in Liverpool for the care and support of people with autism.

In a world first, the centre's in-patient assessment unit will make use of biometric sensors worn on lightweight bracelets to gather physiological data. These will enable expert staff to map a person's anxiety levels and to step in early to reduce meltdowns and distress.

In his launch speech, Chief Executive of Autism Together, Robin Bush, pointed to some staggering figures regarding the length of time that people experiencing behavioural crises or mental health deterioration can be kept at NHS Assessment and Treatment Units that are not autism-specific. He explained that the inability to communicate when under stress and anxiety was an underlying factor in their length of stay and that anything to alleviate those communication problems would have a dramatic impact on people with autism, their families and on over-stretched health services.

The new assessment unit will make use of biometric technology to track subtle changes in functioning such as heart rate, skin temperature and sweat production, enabling carers to respond to distress caused by the environment.

To read more about the appeal, go to www.autismtogether.co.uk/future50 Donate at www.justgiving.com/autism-together and follow the campaign at #FUTURE50.



Hi AuKids,

Have you seen these indoor trampolines? www.bellicon.com/gb_en/shop/introducing-the-bellicon

We bought one two years ago for our now ten year-old when we realized that not having as much access to the garden trampoline in winter seemed to correlate to higher levels of anxiety... plus dangerous climbing around the house, on stair banisters, on furniture etc.

Within hours we were saying we wished we'd known about them years ago. Best purchase ever. Still looks brand new and it's used for hours every day. Anxiety levels dropped enormously. Happier at school, happier all round. More able to cope with changes to routine. Amazing.

He sometimes walks round the outer edge and it's so stable it never tips or wobbles.

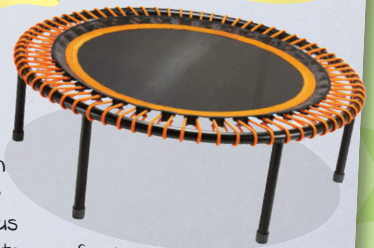
And it's whisper quiet. We know he's on it because of the humming.

They aren't cheap but such good value for money in the scheme of things.

Check out the You Tube video at www.youtube.com/watch?v=nRlcAxpGQ-M We bought ours from this approved UK supplier: goo.gl/xLDEU9

Katie Rogers

READER RECOMMENDATION



AuKids says:

Thanks Katie! Readers do bear in mind that children with autism can have various physical needs caused by hypermobility and other sorts of difficulties. Before investing in one of these, do consult your child's occupational therapist or physiotherapist.

Cover Stars

Harry & Freddie

The boys' dad Glen helps them with these answers.

Harry: 8 years old

Lives: Bramhall, Cheshire.

Likes: Roblox, fast cars, pizza, Maltesers and his cat Chill.

Dislikes: Girly things, dogs, sleeping in his own bed and not having things his way.

If he were Prime Minister: He won't answer this. At least he would be honest though, as he dislikes liars. Oh and he would definitely have a mansion, he really wants one.

Freddie: 5 years old.

Likes: Dinosaurs, counting, colours, his Mummy, hot cross buns, Super Noodles, chocolate digestives, running countless baths, ear defenders and having the TV at 100% volume all of the time. Oh and smashing things like TVs, phones, tablets, glasses and vases on a daily basis. We know he likes it as he does it with such commitment and a smile on his face.

Dislikes: Pretty much not being able to do all of the above whenever he needs to.

If he were Prime Minister: Wow what a world that would be! It would be a very noisy world with lots of broken things. All glaziers would be millionaires.



Super Sundae for Girl Guides!



The 11th Bramhall Girl Guides had fun learning about autism last month when Aukids' co-editor Debby visited them. During their awareness evening, the Guides each made their own Autism Sundae Dessert, a way of explaining the ingredients

of autism which was first featured in Issue 20.

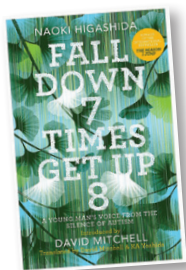
The Guides seemed to really enjoy the session, particularly eating the results!

Next issue we will be featuring a guide to running a similar session.



For sister Izzie's comments, see our Siblings feature on Page 14

Reviews & Prizes



BOOK
**Fall Down 7 Times
 Get Up 8: A Young
 Man's Voice from the
 Silence of Autism**

By Naoki Higashida
 Published by Sceptre
 £14.99 • ISBN 9781444799088

KA Yoshida and the novelist David Mitchell initially translated Naoki Higashida's first book - *The Reason I Jump* - for their autistic son's special needs assistants. It has now been translated into more than 30 languages, making Naoki the most widely translated living Japanese author after Haruki Murakami.

It's easy to why, as Naoki is a uniquely talented writer, offering rare insights into the lived experience of someone whose autism is labelled 'severe' and 'non-verbal'. He painstakingly types out sentences on an alphabet grid as a transcriber takes down what he writes.

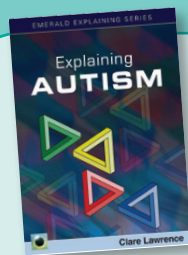
Of the books Naoki has since published, it was this present volume that the translators found to be the most illuminating and helpful. Its aim is to offer practical help for other autism-insiders, with both young and older teenagers in their families.

The book is mostly short chapters written for Naoki's blog between the ages of 18 and 22 and cover a diverse range of topics. Together, they show a young man learning to co-exist with a mind and body not always under his control, trying to find his place in the world and searching for meaning in his life.

It also includes a fascinating introduction by Mitchell where he expertly poses prescient questions about whether Naoki and others like him (such as Carly Fleischmann, Ido Kedar and Tito Mukhopadhyay) point to the uncomfortable possibility that the current mainstream assumption that people with severe autism have matching severe intellectual disabilities is our decade's big bad falsehood about autism.

This is a truly remarkable and important book, and should alter your perspective on autism.

Mark Haworth,
 Staff writer and support worker



BOOK
Explaining Autism

By Clare Lawrence
 Published by Emerald Guides
 £9.99
 ISBN 9781847161642

When Clare Lawrence's first edition of this book came out, then titled *Explaining Autism Spectrum Disorder*, it was the best round up of autism that I'd ever read and we still recommend it to parents today. I couldn't remember why I thought it was so good, so I was very grateful for the refresher that came with this second edition, *Explaining Autism*, in which Clare has successfully ditched the rather negative 'disorder' term.

There's so much published on particular aspects of autism these days that it can be hard to find a guide that gives a basic overview of autism for those new to the condition, their friends and family. This is it!

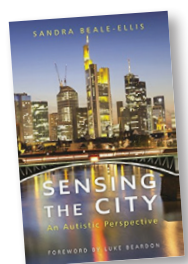
The author gives a succinct round up of each aspect of autism, both according

to the previous diagnostic criteria and according to the more updated version. After each explanation, she illustrates her points with small scenarios involving both adults and children with autism. All the jargon is covered, such as the meanings behind Theory of Mind and Weak Central Coherence.

There isn't too much depth in this, it's humorously and sagely communicated and it's just perfect for a beginner. As the book continues, theory is translated into practice in the chapter *What Does Autism Look Like?* Finally, Clare rounds off with some key strategies and there's a useful chapter about inclusion in school and work.

When I last reviewed this book, I noted that a summary this good can only be written by someone who has a genuine understanding of autism. I stand by that. This book should be compulsory reading for anyone connected with the condition. Clare has done us all a great service in writing it.

By Debby Elley, Co-editor



BOOK
**Sensing The
 City - An Autistic
 Perspective**

By Sandra Beale-Ellis
 Published by Jessica Kingsley
 Publishers
 £12.99
 ISBN 9781849056359

The author of this book has Asperger's Syndrome, holds a Post-Graduate Certificate in Asperger's Syndrome and lives in Kent with her husband, who also has Asperger's.

The book offers a personal account of the sensory experiences had in the city for an autistic adult, taking readers on a humorous, honest and informative sensory journey around the world. It should appeal to any adult who wants to learn more

about the sensory experiences of autistic people in the city – and could be a useful resource for anyone planning an event or trip with autistic adults.

This is a short and easy read, with its small chapters making it perfect bedtime reading or ideal company for the morning commute. The book fulfils its promises, often making me laugh, and finding creative ways of immersing me into the sensory world of an autistic person. It doesn't get caught up in research or being too advisory; instead it saunters along in a light, enjoyable and meaningful way. I'll be recommending it to my fellow Post-Graduate students – and I would certainly recommend it to readers at home!

Adam Holland is a support worker completing an Autism Studies Post-Graduate course at the University of Kent.

BOOK
The ASD Feel Better Book By Joel Shaul

Published by Jessica Kingsley • £15.99 • ISBN 9781785927621

This review is by Bobby (and one of his best friends Reece, who also has autism).

For us, this book is relatable because it mentions a lot of aspects about our autism and other people's.

This book has tips on how to understand autism techniques at a different level, also this is a simple visual guide meaning any kind of autistic person can read it, whether in words or in pictures, whatever floats their boat.

Joal Shaul (the author) really hits hard on topics such as stress, anxiety and life as an autistic person in general etc. and really helps you understand what autistic people must be going through in these states at times.

We really give this book an 11 out of 10, with its simple design, its strategy on how to handle autistic people (with stress, anxiety, problems, etc.). It can really be a hassle, you know. And that review comes from two autistic people, best friends, supporting one another.

Bobby and Reece, age 14





BOOK
Exploring Depression, and Beating the Blues

By Tony Attwood, with illustrations by Colin Thompson
Published by Emerald Guides
£13.99 • ISBN 9781849055024

I have worked in the field of autism for nearly 20 years now and am constantly developing my knowledge and understanding. I love working with the young people I meet and working together to find out ways of helping improve their lives.

In my current role, while based at Inscape House School, I work with pupils in a variety of mainstream schools. The majority of pupils I work with are of high school age, have an autism diagnosis and could be regarded as having Asperger's.

Many of them have issues around depression and having conversations about suicidal thoughts are becoming more and more common. Although we have help from services that support around mental health, they are not working with our students on a daily basis in mainstream settings.

Tony Attwood is one of my favourite autism related authors and I have even been known to take his books away with me as a holiday read! His latest is one such book.

Attwood starts by setting out why people with autism seem to be more prone to

depression. Although I was aware of this, it is still shocking to read that 66% of the autism population have suicidal thoughts compared with 16% of the neurotypical population. No wonder it seems to be such a major focus for me at work.

Three students I am currently working with immediately sprang to mind as I read the book.

What I look for in a book is practical help; this is where this book really comes into its own. The first stage focuses on identifying and evaluating what is going on and acknowledging the positives. Then the book leads the reader through how to beat the depression, giving ideas for activities and action plans. These are really useful and are broken down into clear stages making them very autism friendly, as one would expect from such a brilliant author.

Years ago, when I first starting having conversations with students about self harm and suicidal thoughts, I was terrified I would say or do the wrong thing and only make things worse. This book really helps with that and while pointing out the need to access specialist mental health support, it gives clear guidance about handling the realities we are dealing with such as self harm and thoughts of suicide.

We all strive to help improve the quality of life of the young people we work with and this book is another great resource in my ever-expanding toolkit.

Greg Loynes, Assistant Headteacher, Inscape House School



Giant Book GIVEAWAY!

AuKids has **TWO** copies each of **Explaining Autism** and **The ASD Feel Better Book** to give away plus **THREE** signed copies of **15 Things They Forgot to Tell You About Autism**.

To win, all you have to do is email us with your name and address to competitions@aukids.co.uk no later than May 31st 2018. Winners will be chosen at random. Put either FEEL BETTER, EXPLAINING AUTISM or FIFTEEN in the subject header to be in with a chance of winning that title. You can enter by post at AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE.

Light-up Learning

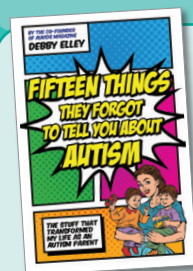
We've just tested a light-up drawing board that is, in AuKids' official terms, **WOW**. Kootchy Products' rewriteable LED board works with a colour-changing remote control. Choose the colour LED you fancy, and then select the effect – flashing, fading or still - at the touch of a button. The kit arrives with six special markers and your drawings are beautifully backlit. Highly motivating, it's also a fantastic sensory aid for mark-making and pre-writing skills. It comes with a hanging chain and a power cable, plus soft cloths for wiping off the marks with water. Read reviews from special needs parents at www.kootchyproducts.co.uk



WIN an LED Board!

Fancy a rewriteable LED board (30cm x 40cm) worth £34.99?

To be in with a chance of winning, just answer this question: On the Kootchy Kids section of the Kootchy Products website, there is a message written on the 50cm x 70cm LED board. What is it? Email your answer to competitions@aukids.co.uk no later than May 31st 2018, or send a postcard to PO Box 259 Cheadle Cheshire SK8 9BE. The winner will be drawn at random.



BOOK
Fifteen Things They Forgot to Tell You About Autism

By Debby Elley
Published by Jessica Kingsley Publishers
£12.99 • ISBN 9781785924385

This book is brilliant, it's the best book ever written on autism...oh, Adele, hi... what do you mean I can't review my own book? Okay then, you do it...

Hello everyone. My name's Adele. Now that co-editor Debby Elley is safely out of the room, I can give you an unbiased account of her first book.

The first thing that I thought when I picked up this book and read the title page was 'Hooray for Debby Elley!' When I recommend Aukids to parents, it is because I know that the ideas and advice are well researched, brilliantly explained and handled with respect, care and humour. So when I heard that Debby was writing a book I was excited.

'15 Things They Didn't Tell You About Autism' reads like a best friend's guide to autism. It will make you laugh, may make you cry, could make you feel less isolated and I suspect and hope that after reading it a lot of parents will feel more empowered. This book doesn't patronise

or preach. Debby paints a vibrant, truthful picture, written from personal experience raising her twin sons Bobby and Alec. She also shares her experiences and the explanations of autistic adults she has met including Aukids' very own Tim.

Debby signposts books, resources and courses, which will save parents trawling through a lot of information. She describes herself as an 'owl', who is constantly researching and seeking understanding and this book will save other parent 'owls' a lot of time and tiredness.

What I love is that Debby doesn't assume to know. She is always learning, always having those wonderful 'aha' moments and those retrospectively amusing 'whoops' moments.

This book is honest, down-to-earth, sometimes opinionated, surprisingly funny and those '15 (well actually 16) things' are based on sound knowledge, experience and a lot of listening.

I've been waiting for this book with anticipation so that I can start recommending it to parents.

Thank you Debby! You have done yourself, your wonderful sons and Aukids readers proud.

Adele Devine, author, special needs teacher and founder of SEN Assist



“ I have a 9 year-old son diagnosed as high-functioning autistic. He is mostly managing really well apart from he is terrified of dogs and cats. I think it's their unpredictability coupled with some bad experiences of friendly dogs that jumped up at him when he was younger. What do we do? ”



Cartoon by Michael Barton, author of *It's Raining Cats and Dogs* and *A Different Kettle of Fish*



Debby Elley

Co-editor of AuKids magazine

his behaviour a dog or cat may like or dislike. So, help him to understand that a dog may just be as frightened of him as he is of a dog.

A sudden bark, for an autistic person, is a bit like the sudden noise from a vacuum, a hand dryer or a balloon. A lot of autistic people hate these items because they all have the potential to make sudden noises. You could put ear defenders on him when you go to the park so that he knows no sudden noises will bother him, but he also needs to be aware that dogs tend to bark when they are excited and happy and not always when they mean harm.

The key is building up tolerance slowly and stopping well before the child has had enough. So, reward five minutes in the park and gradually extend it. Let him tolerate pets from a distance first, gradually moving closer.

When kids with autism have a special interest, it floods their brain with happiness and this can sometimes combat anxiety (see Tim's *Inside Angle*, where he mentions positive images derailing negative ones). So perhaps every time you spot a dog together, you can give him a token with a favourite image on it, building up to buying an item connected with his interest after 5 tokens. Linking special interests to something perceived negatively can really help.

Firstly, I think it's a very good observation to say it's their unpredictability - it most probably is. People have confusing body language but at least they can be relied upon most of the time to be tame rather than aggressive. With animals, not reading the signals could mean something very different.

What may very well help is teaching him what cats' and dogs' body language means, so he knows the difference between a dog who looks excited to see you and one who is being aggressive. I'd do this starting with non-threatening images from stories like *Hairy Maclarey* by Dame Lynley Dodd, then maybe build up to analysing some funny You Tube videos of pets being very, very silly. There's nothing like a dog aiming for a sofa and missing, to make you see that pets are mostly loveable idiots.

It would also be a good idea to put him back in control by telling him what aspects of



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

Ah yes, your little chap is by no means on his own here! In the first instance I would suggest that he needs as much support as possible to generally reduce stress - stress/anxiety do not make for good times, and ongoing exposure can lead to all sorts of not fun times ahead in the longer term. And I don't mean in the verbal reassurance way - don't, for example, go down the route of "don't worry, the dog doesn't mean any harm..." etc. - if he's stressed about the dog he'll be stressed about the dog, irrespective of what you might say about it!

I would be tempted to find somewhere where you can guarantee a dog/cat free environment in which he can genuinely relax but still get out - no idea if this is practical for you, but at this time of year many beaches are very empty and some have total bans on animals, for example.

The other thing that might be worth considering - and I'm going out on a limb, here - is visiting a cat sanctuary or similar where (if you did

some preliminary work) it would be possible to view cats (who are less threatening than dogs in the main) without interacting, as they will be closed off. In some places they will even separate out the kittens and allow a petting time - perhaps if he starts off with kitten contact he might enjoy it?

Lots of the animal issues are sensory and, sometimes, the negative sensory side of animals (unexpected barking is the classic) can actually be off-set by the positive side - the feel of fur, for example. One of my favourite things to do of all time is to sniff my dog! Having control of a situation can also be very important to gain confidence - so if you know of a non-bouncy non-barky kind of quadruped he could visit (providing your son could ask it to leave at any time) this might be a great way to maintain his control but engage in a positive manner.

Of course, while the issue might be with the slightly larger variety of animal and the lack of control while outdoors, there would be no harm, I suspect, in exploring furries and featheries in general. Does school have a small furry that kids can take home to foster for one night? Or do you know of anyone who would loan a person-friendly cuddly beast? If you lived my way, I'd introduce Dit and Dot, two very friendly small silver chickens - though Sandy Pancake Waggy Eyes (dog) might be a little bouncy!

Seriously, a controlled introduction to animals could do wonders in terms of turning a negative into a positive. The positive power of animals cannot be underestimated for so many autistic children (and adults), so if there were any chance of balancing out the negative, then go for it!



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

First of all, we need to acknowledge that a healthy respect for dogs and cats is okay. But, like anything else, if a fear is making it difficult to do everyday things (like going for walks), it's a problem.

Needless to say, not knowing what to expect from something or someone is anxiety provoking for everyone. Bringing some predictability to dogs can help reduce your son's anxiety.

A good first step is to get your son to become a 'dog scientist'. That is, he can learn about dog body signals/language. I like to prompt children to do this kind of research to help other children – this takes the focus off your son – altruism usually wins.

You and your son can make up a chart that describes and shows what happy, scared and angry dogs look like. Note what a dog's tail, ears, eyes and mouth are doing when they are

happy, scared or angry. This will make the whole thing much more objective with way less emotion.

Part of his research can be from watching television. Also, look on the internet for more examples or when you're driving in the car. Once your son has done some of the research, it's time to get closer to dogs. Find a local dog shelter where the dogs are in cages and your son can feel safe. All of these experiences should focus on finding and refining features on the chart and not on your son's fears.

After your son has completed his research, the next focus is on how to respond to different dog body language. Start by practising just being calm with no dogs around. Help your son do what I call slow Turtle Breathing – "in one-two-three and out one-two-three" – focusing attention only on the air coming in and out. Be sure to tell him that if his brain and body are calm, he can think better and make better decisions.

Once your son can calm his body and brain, he needs to learn about how to respond to happy, scared and angry dogs. Let him know that if he's calm, dogs will sense it and they'll be calm, too. Start by meeting friendly, well-behaved dogs. Keep his response simple – he takes some Turtle Breaths, says "Hi, dog", doesn't look directly in the dog's eyes, and walks away. Don't make him touch the dog – a lot more desensitization needs to occur first.

Have a huge celebration once he's been able to follow these simple steps with friendly dogs – every step is a huge accomplishment.

My research about dog body language

	Tail	Ears	Eyes	Mouth
Happy	Down, maybe wagging	Up	Relaxed, not too wide-open or slitty Looks at people	Closed or little bit open
Scared	Down really low, might be between his back legs	Down	Small Looks away	Tight lips
Angry			Big, wide open Staring at a person or another dog	Grins, you can see his front teeth

Further Information

Attacking Anxiety: A Step-by-Step Guide to an Engaging Approach to Treating Anxiety and Phobias in Children with Autism and Other Developmental Disabilities

By Karen Levine and Naomi Chedd

Published by Jessica Kingsley Publishers



Brian and the Big Black Dog

(2-5 years): A book for children who are scared of dogs: Volume 8 (The Adventures of Brian (2-5 years))

By Nicola Edwards

CreateSpace Independent Publishing Platform

EDITOR'S NOTE: We'll be honest we've not personally seen this book but it looks spot on!



Dr Paul Holland

Paul is a Chartered Psychologist specialising in Behavioural Consultancy and Executive Function Coaching. Paul has worked with children and adolescents with ASD, ADHD and other learning difficulties for over 20 years. For more information about Paul and what he does, please visit his website: www.drpaulholland.org

have long tails; some have long hair while others have short hair. The same (but to a lesser degree) can be said of cats.

In terms of what you can do, I would:

1. Teach your son about dogs and cats, aiming for generalisation by covering all common varieties. You can do this via play or sorting activities.
2. Write a Social Story™ about each animal explaining that they come in different shapes, sizes and colours and highlighting some of the things that he can expect from these animals. Include a very important rule here:

"Always ask before you stroke a dog or cat" or "Do not stroke dogs that you do not know."

For information on how to write a Social Story™, see Issue 15 of AuKids' online archive.

3. De-sensitise your son to a known and very gentle dog (or cat). This will have to be a **very gradual process**, ensuring he does not become upset at any stage. Some steps could be:

- a. Look through a closed window
- b. Look through an open window
- c. Walk past at a distance (with the dog on a leash ensuring no sudden movements)
- d. Gradually walk closer

Always reinforce him with a preferred item after each step!

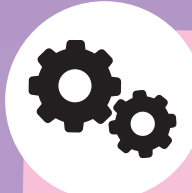
And remember...to be wary of unknown dogs is a good thing!

For individuals with autism, fears tend to stem from a combination of not knowing accompanied by the often unpredictable nature of the world around them. Dogs and cats often behave in ways that we cannot predict...and this can be anxiety provoking.

Individuals with autism often experience difficulties with categorisation and generalisation. This means that even though our children with autism may understand that a Labrador is a dog, they may not automatically transfer this understanding to all dogs. Dogs come in varying sizes, lengths, colours, shapes; have different shaped ears, mouths heads and bodies; some have tails while others do not; some have short tails and others



Family Fund has helped over 600 families raising disabled children to use tablet computers since 2015 through its popular Digital Skills Programme. Based on their experience of helping families with children who have specific and additional needs to use tablet computers, including many who have autism, here are their top tips to help parent carers to get the most from their tablets.



1. Set up the device yourself

This may seem obvious, but it can be tempting to simply hand the tablet to your child for setting up, or set it up in haste and forget your password or passcode. If you do this, you could end up being locked out of the device and it can be almost impossible to get back in. Make time to set up your tablet and use passwords and passcodes that you'll be able to remember.



3. Apply parental controls

Most tablets enable parents to implement some level of control. This can include restricting the websites and videos your child uses, managing their ability to download or delete apps, and preventing them from accessing your email and other accounts. Usually, parental controls can be found in the 'settings' area of your device.

In the case of iPads, there's also Guided Access, which allows a whole new level of parental control, such as setting timers to close apps after a fixed amount of time, setting the volume so your child can't keep turning it up, and freezing specific areas of the screen. Visit www.support.apple.com and search for 'Guided Access' to learn more.



5. Take advantage of the help available

As well as Family Fund's Digital Skills Programme, there's a great deal of help available, whatever your digital skill level. Many libraries offer workshops and some technology companies also provide free support. For example, Apple run small group workshops and one-to-one sessions for iPad and iPhone users in their stores; simply search online for 'Today at Apple' and book a session using your Apple ID. Samsung also offer in-store support to use Samsung tablets – there's no need to book, just turn up with your Samsung tablet or smartphone. Charities including NSPCC and AbilityNet can help too.



2. Don't be afraid!

Children often seem to know so much more than we do about technology, and aren't always the most patient teachers if we ask them for help! One of the reasons they are so 'tech-savvy' is because they're not afraid to try things out. It's difficult to break your tablet by simply pressing buttons, so spend time playing with it or get some free training to understand what it can do. In particular, find your way around the settings. That way, you'll have more confidence when managing your child's usage.



4. Find suitable apps

Not all apps are useful or high quality, but don't despair – Family Fund has a Pinterest board called 'Useful SEN Apps for tablets,' which brings together apps that families raising disabled children find helpful. There's also a free app called 'Autism Apps' by TouchAutism which includes reviews by parent carers. These can be really useful, especially if you're thinking of downloading a paid-for app. Search for 'Autism Apps' in the app store.

According to Jenny Laycock, Programme Support Manager at Family Fund...

It's clear that tablets can support learning and development in ways that the offline world can't. This can be especially true for children with autism who sometimes find online interaction easier than face-to-face or who maybe don't learn well in a classroom environment. Learning through tablets is most effective where parent carers are involved in their child's experience of the online world and Family Fund's Digital Skills Programme is designed to support parents raising children with autism to do this.



Family Fund
Helping disabled children

Family Fund is the largest UK charity providing grants to families on low incomes raising disabled or seriously ill children for essential items such as kitchen appliances, clothing, bedding, sensory toys, computers and tablets, much-needed family breaks and more.

Find out more information at www.familyfund.org.uk or by calling 01904 550055. You can find out about Family Fund's free tablet training programme by visiting www.familyfund.org.uk/digital where you'll find a link to Family Fund's Pinterest board.

Shutdowns - The Invisible Enemy

Tim Tuff is AuKids' researcher, distributor and autism advocate. He gives talks around the country of his experiences of autism. He is also part of the Greater Manchester Autism Consortium, helping to achieve more autism awareness within the region. See AuKids' YouTube channel for more from Tim.



A lot of people talk about meltdowns, but there's something else that they don't seem to mention, and it's shutdowns. I tend to experience shutdowns rather than meltdowns. For me, a shutdown is caused by my environment. A meltdown would be caused by a particular challenge that I feel I can't face. I avoid meltdowns as an adult, because I plan so that they don't happen. What I can't always control is my environment.

Shutdowns aren't written about as much as meltdowns because they are not what people see as violent or challenging. People don't always notice that someone has 'zoned' out either – especially if they are non-verbal.

A shutdown is my body's response to overload. It can be sensory overload, such as when there are too many sights and sounds at once. Or, it can be a reaction to a busy environment and crowds. It can even be caused by temperature.

During a shutdown I can't physically run away (even though I would like to), but I switch to a form of 'absence' that helps me to cope with overload.

Sometimes the environment can change without other people realizing – for instance, I am experiencing something through my senses that causes a disturbing flashback.

Dates or objects that have sad memories will affect me, and anything that triggers a memory of a trauma is likely to cause a flashback and therefore a shutdown.

When other people think of flashbacks, they imagine a brief but vivid image. My flashbacks are far more immediate. I feel exactly as if something is happening all over again.

My flashbacks are the worst thing about my autism, because they're like 'a waking nightmare'. During them, it feels as if two timelines collide – the present with the past.

During a flashback, I used to shake my head in order to try and rub out images. Now, I try and find something I like – like a postcard – to distract me from bad thoughts. I can 'jump in' to positive images in the same way as negative ones and use them to help me.

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“Positive pictures can derail negative thoughts”

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If you show your child a positive picture when they're getting upset, you may be able to distract them enough to derail the negative thought. For example, my train was late this morning but a train arrived the other side with my mum's house number on it; this positive distraction was enough to stop me from panicking.

When I do have a shutdown, I become unconscious of the world around me and I am unable to see. I become disorientated as well and can't communicate. It may be quite a few minutes after the shutdown before I am able to form words.

If you look carefully, you can spot a shutdown about to happen in someone like me. I may start to stare into space or go unusually quiet. I may start to flap my arms at my sides (to help me with my internal sense of balance). Sometimes my face goes a little red. I sometimes start to twiddle my hair (what's left of it!).

I can physically feel a sensation building up in my body from my feet to my head, and it can happen in seconds.

Because I have very little warning, I am unable to tell a person that it is happening. The shutdown 'knocks my voice out' and I may not be able to warn you – although if I have time, I may grab your hand.

To help during a shutdown, someone needs to sit down in a quiet space with no distractions. Simple language and reassurance that I'm safe and ok helps a lot. One person is all I need – too many people would cause me to panic.

I have a special comfort toy – my mini beanbag that I call 'Haggis' because it's tartan! Haggis is something familiar to touch when I get upset.

Sometimes spinning objects, or even myself, helps. If in public, I tend to spin a bottle top or something close to hand.

You can also try to refocus the shutdown by telling me about things that interest me or making me laugh. Occasionally this can

distract me. When I am in this 'zone' I cannot hear most things, but some of it gets through and can distract me. Do not persevere if I'm really upset, though.

Waiting it out with me and making sure I'm safe is the best thing to do.

Afterwards, I blink and shake my head – it's like awakening. I find shutdowns draining – eating something sweet or having a drink helps. The rest of my day hasn't been affected. Although at the time it's disturbing for me, it seems to help me deal with past events by putting them in a 'box'. In this way, I suppose they help me to cope.

Tim was interviewed by Debby Elley for this article. Photograph of Tim Tuff courtesy David Laslett.

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- Jarlath O'Brien on why exclusions of pupils with SEND are on the rise
- Simon Knight outlines a new approach to improving staff's SEND skills
- How to support children with autism during PE lessons
- 4 Lesson Plans




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Time for the Big Move

Preparing for secondary school is daunting for any child. But for a child with autism, their transition from the security of a small primary school to a large mainstream secondary needs to be handled with particular care. The key is to start well advance, with lots of preparation. Here's some top tips compiled by AuKids and the Wraparound Partnership.



Two years in advance

- ★ Start gradually introducing the idea to your child that they will be moving to another school.
- ★ Talk to the primary school's SENCO (Special Educational Needs Co-ordinator) or teacher to determine which schools in the local area would be best to support your child.
- ★ Get your paperwork organised and in date order. Collate relevant school reports to show new settings.
- ★ Visit as many suitable settings as possible.
- ★ Decide what's important to you and your child beforehand so that you have the same questions to ask of different settings and can compare them.
- ★ Show your child pictures and videos of the school and attend any open days and school events which are held with them.
- ★ Decide both a first and second choice of schools along with the reasons you feel these are best suited to your child. It's best to make notes straight after looking at a school so that you're able to justify your decision on paper with clear recollections.
- ★ Ask the school about how they adjust for specific needs, e.g. sensory difficulties.
- ★ Think about how your child will get to the new school - will they require travel arranging by the local authority? If yes, have this discussion with them early on.
- ★ Keep track of dates. Make sure you are aware of when you need to finalise your school choice.
- ★ When pointing out your first choice of school, make clear points: what your child's needs are and how you feel the school you have chosen meets those needs.
- ★ Keep looking after you've found your first choice. Don't let a second choice be an afterthought.

With six months to go...

- ★ Some areas hold transition training sessions for groups of autistic pupils during the holidays. It's worth looking at your local authority's *Local Offer* website to check, or asking the new school.
- ★ Arrange regular taster visits with the new school's SENCO and/or class teacher for different times of the day.
- ★ Ask your child if they would like to take a friend, teaching assistant or familiar person along with them.
- ★ Watch out for open mornings designed especially for special needs children.
- ★ Allow your child to take photographs at the new setting (or ask for them) and use whatever works well for them as visual supports.
- ★ Arrange for someone from the new school to visit your child in their current setting (preferably form tutor).
- ★ Encourage your child to discuss any anxieties they may have.
- ★ Practise the journey to the new setting.
- ★ Share information with the secondary school, particularly classroom tips on triggers and how to keep anxiety and distress to a minimum. We advise keeping a classroom tips record for the final few years of primary school, noting difficulties as they happen, how they are managed in the short term and what you're working towards in the long-term. You can request this to be an Appendix to the EHC (Education, Health and Care) plan.
- ★ If the child has an EHC plan, ensure the new school is provided with a copy well in advance of them starting at the new setting.
- ★ Ask the new school to nominate a buddy to help the child settle in.
- ★ It's worth asking whether the school carries out any peer group training in autism – many don't but if they do it's the mark of a good school.
- ★ Agree a settling in plan for the first day/week/month with school.

Things your child should know on the first week

★ We might not get it perfect all at once but we can adjust things with school as we go, so don't worry if everything's not right straight away.

★ You don't have to make friends straight away. In fact when people do, they often end up changing them!

★ Have extra chill out time at home! (They will need it to self-regulate after the extra demands on them).

★ It will feel very different – and that's okay!

Ask Mainstream Secondary Schools:

How many autistic children do you have at this school? Can I speak to a parent like me?

What happens during unscheduled times e.g. Break and lunchtime? (For SEN students, there should be somewhere supervised they can go away from the chaos of huge playgrounds).

Are teachers trained in autism?

Where can children go if they need some time and space away from noise?

What happens at lunchtime? (Is it just one large hall or are there smaller, quieter ones they can go to?)

What adjustments can be made if my child can't cope with a full timetable?

Will they have one T.A. throughout the day, or several? (There are advantages to both methods but your child should know in advance what the situation is and preferably have photographs of anyone working with them).

Are children allowed to type instead of writing lengthy pieces of work in school if they struggle with writing? (This is not an horrific request, it's a reasonable one).

N.B. It's not just the responses to these answers you're listening for, it's the way that they are given to you. Trust your instinct. Do they sound flexible? Are they willing to make adaptations? Are they used to what you're asking?

About Wraparound

Wraparound Partnership is a team of six IPSEA trained advisors, most of them parent carers (IPSEA – Independent Parental Special Education Advice). The Wraparound Partnership offers independent, private support to families in the North West with Education Health and Care Plans (EHCPs) up to and including tribunal stages. The team also advises on other special needs matters including social care and personal budgets. The Wraparound team works some evenings and at the weekend so that they can provide quick support. Costs are set at £120 for an initial 6 hours of support over the course of a year. To find out more go to www.wraparoundpartnership.org, call 0161 872 6879 or email hello@wraparoundpartnership.org

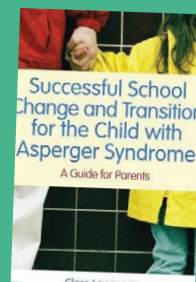
Further Advice

IPSEA offers free advice at www.ipsea.org.uk

BOOK
Successful School Change and Transition for the Child with Asperger Syndrome: A Guide for Parents

By Clare Lawrence

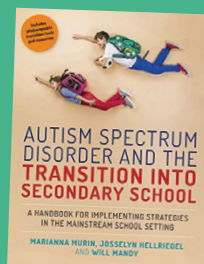
Published by Jessica Kingsley Publishers.



BOOK
Autism Spectrum Disorder and Transition into Secondary School

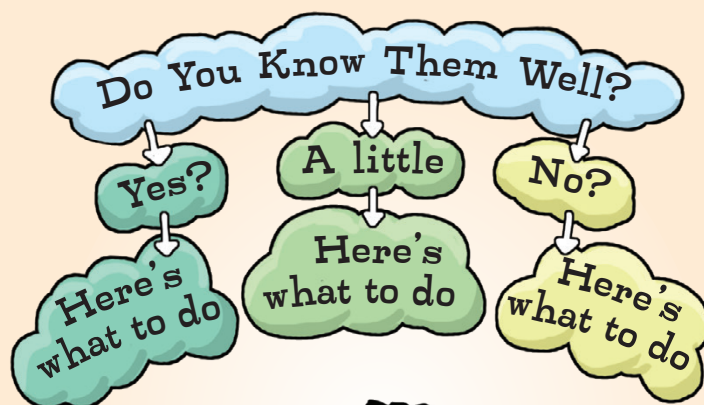
By Marianna Murin, Josselyn Hellriegel and Will Mandy

Published by Jessica Kingsley Publishers.



Living by The Rule of Thumb

How to make social skills easier for your autistic child By Debby Elley



Autism, as Clare Lawrence says in her brilliant book *Explaining Autism* (see *Reviews*) is a social disorder, not an intellectual one.

Social skills are the hardest thing to teach someone who lacks them. Why? Because they change! They vary from place to place, from person to person. What you can say to one person, you can't get away with to another.

I mean, in a sauna, it's appropriate to sit in a small room wearing just a swimsuit alongside members of the opposite sex whilst not saying a word. In any other setting, this would be considered distinctly weird. Yet we accept it. We adapt, we adjust...All very confusing if you're autistic and don't have the flexibility of thought to take different situations and their accompanying rules into account.

In Issue 15 (available for subscribers on our online archive) we covered the use of Social Stories™, which we like to

call 'maps of the social world'. They are pre-prepared guides that you can write for your child explaining what to do in specific situations.

But how do you live in between those Social Stories? How do you navigate through the wealth of subtle interactions that we face daily?

My son Bobby is 14 and social confusion means that he often says 'Sorry about that,' straight after he's made a comment. It's a kind of blanket phrase to cover all potential wrongdoing.

There is no getting away from the fact that social rules are complex. There is also no getting away from the fact that no one on the autism spectrum can possibly learn the thousands of separate rules governing each type of setting - (then they'd have to start again for a different culture or country). Social rules are so subtle that sometimes what you can get away with

depends on personality alone, let alone all the other factors.

Yet do we avoid learning to cook because we can't be Nigella Lawson or Jamie Oliver? Nope, we just cook using more basic methods. That's my theory behind the rule of thumb technique.

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Socially skilled parents sometimes think that the answer to everything is long explanations. However, the autistic mind usually copes far better with visual methods that appeal to a logical and systemising way of thinking.

The rule of thumb technique is this:

- 1 Have confusing social situation flagged up by either your child asking a question or them failing to negotiate a situation.
- 2 Think of the underlying questions you ask yourself when faced with that situation. What decisions do you make quickly that determine how you should act?
- 3 Create a rule of thumb based on those situations.
- 4 If time, make a flow chart for it like the one below. If not time, just write it down.
- 5 Give rule of thumb to your child, explaining that it won't cover **EVERY** situation but that it will help with a lot of them.

Here's an example. Last weekend, Bobby and I went to the GAME shop, which is his favourite place. After what seemed like an eternity looking around, he finally purchased something, and in doing so he said to the female shop assistant 'Cool retro top!' She thanked him, but then he said 'Sorry, sorry...' and confusion followed him all the way down the High Street.

Okay, I thought. What's the social rule here that will make it easier? When is it okay to comment on someone's appearance? Why was what he said actually okay when he didn't know her?

Well, it's okay to comment on someone's clothing if you're already speaking to them, but not okay to grab someone in the street to comment on it.

Taking it slightly further in my mind, I realised that his compliment was okay because it was limited to what she was wearing.

It's fine to admire someone's top, but not to admire the body in it - or someone's hairstyle - unless you know them extremely well.

And if he'd criticised her top, that would not have been appropriate. So, whereas it's socially acceptable to make positive comments, it isn't to make negative ones.

This all comes automatically to me, but not to him.

You may not even agree with my rules, that's how subtle they are.

So, having taken several minutes to dissect my own thinking and think 'When is it okay? When is it not okay?' I give Bobby a Rule of Thumb. This has taken several minutes of me distilling complex information into a simple rule, ignoring anything too subtle. What we're looking for is what will get him through most situations without being entirely inappropriate.

Rules of thumb may be clumsy and they may not be perfect. For autistic people, however, they are important. In a world full of abstract, unfathomable and vague notions that they cannot pin down, rules of thumb act like numbers. They are set, they are certain, they follow a pattern and can be learnt. It's a bit like those people with autism who have learnt to focus on someone's forehead to feign eye contact. They're faking it in a way that will help them get by.

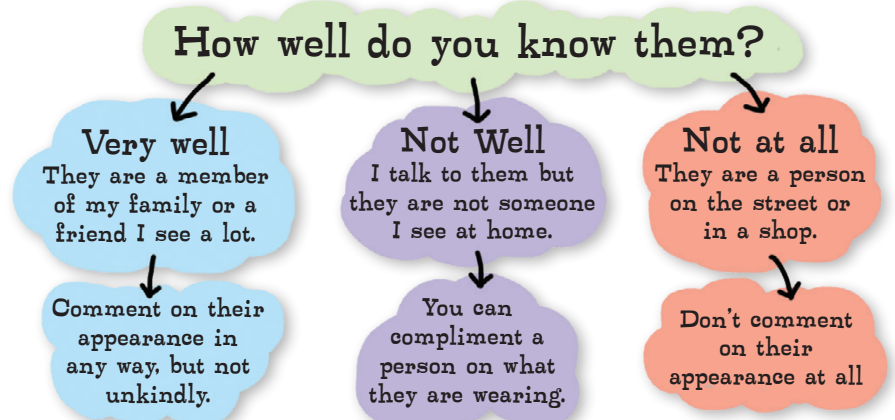
An important point to make here is

that Rules of Thumb appeal to the autistic way of thinking. Socially skilled parents sometimes think that the answer to everything is long explanations. However, the autistic mind usually copes far better with *visual* methods that appeal to a logical and systemising way of thinking.

Reducing uncertainty in this way also reduces social anxiety. Social anxiety can be crippling for people with autism. It isolates them even when they'd rather be with others. It narrows their world. If we can give them the confidence to navigate the world through making it simpler, we can affect their mental wellbeing in the long term.

So, any time your child gets stuck, take some time by yourself to simplify and translate the rule. It may not be a perfect solution, but it's better than leaving them to work these things out for themselves.

Commenting on Someone's Appearance Flow Chart



Notice that the flow chart defines what knowing someone well means. You will need to test your child's judgement in this respect. They may feel that their teacher is someone they know very well, and so we've defined 'Not Well' as someone who you would not see in your own home.

Lots of children have confusion about who it's best to be familiar with. It's quite a good idea to do some further work on this as a

starting point. I like the onion ring diagram, with ME! in the middle. Ask your child to list people according to the social rings closest to them, moving out towards acquaintances on the outer layers. This is a good starting point for any further work on social skills.

Our kids may lack the ability to negotiate this complex social world, but with our help, they can make up for them just enough to get by.

Good luck!

CELEBRATING Super Siblings!

The unsung heroes of our families, siblings develop such fabulous skills as children that they often grow into wonderful, caring adults. We spoke to some siblings of all ages and asked them to tell us honestly what life is really like living with an autistic brother or sister. By the way, we deliberately approached some older siblings, as we felt their messages would be helpful to younger siblings reading this article.



Ben is 10 and lives in Leicestershire with his brother Harry, who is 13.

“Harry (shown here with his thumbs up) goes to a special school. He can talk now but sometimes it is difficult to understand what he means. He likes being on the iPad but gets cross if the WiFi stops working. He is very funny and makes me laugh”.



Mathilda is 27 and lives in Nottingham. Her brother Alfie is 25.

“Alfie is non-verbal, and uses visual symbols via an app. It’s unclear how much language he can understand, though probably more than he appears to. He enjoys music (especially guitar) and puzzles”.

Can you remember when you found out about your sibling’s autism? What was your reaction?

ADAM My first reaction was one of frustration and sadness.

MATHILDA Alfie was diagnosed in infancy. I was also very young, so I do not remember being told, it was always just a fact of life.

BEN When Mum talked to me about autism I didn’t know what it meant at first.

ASHLEIGH I didn’t really react, he was still Patrick, the word autism didn’t really mean anything.

ISOBEL My mum told me that Harry had autism last year. I’ve known that Freddie has it for two years. I was happy finding out because it means I can look after them.

Growing up, what main ways was your life different to your friends because of autism in your family?

ADAM I think the main times I noticed the differences were in the everyday things... going for a family shop or when having family or friends around the house. They didn’t really ‘get’ the autism. People weren’t really able to empathise, it was more sympathising (and I didn’t want sympathy!).

BEN Going out and about isn’t as easy for us. Harry doesn’t like waiting or being in noisy places. We don’t eat out very much. Harry is tube fed and gets bored if he has to sit while we eat.

MATHILDA We didn’t have normal sit down meal times. My brother could never sit still so we just ate food when it was ready and

wherever we were. Also, it was very hard to have friends over to stay, knowing my brother might appear, barely clothed, at my bedroom door.

ASHLEIGH I grew up a bit quicker. Patrick would run off a lot, so days out were often unpredictable.

ISOBEL Our family stays in a lot and we don’t do much stuff outside because when we go anywhere Freddie cries and Harry never wants to go out at all because they don’t like noises. We only go on holiday when it is really quiet too so that it’s easier for the boys.

Did you ever get resentful or angry about the autism?

ADAM At the beginning (and for many years after) I was quite angry about autism – because it was a name for something that had caused my brother and family a lot of pain and heartache. I suppressed my feelings and I didn’t want to open up to my family about it because the focus was on Matthew – and I wanted it to be that way.

BEN Yes. He can’t do sports with me or play with me the way my friends’ brothers do.

MATHILDA Yes, especially when I was a pre-teen/teenager. Without going into too much detail, my brother didn’t have much understanding of privacy, which is obviously very important to teenage girls. I had to have a hook-lock on the inside of my bedroom door to keep him from coming in and taking my things. I was so busy being hormonal and angsty and didn’t have time to think about how he didn’t necessarily understand my need for privacy.

ASHLEIGH I felt he got more attention but my anger wasn’t with him, it was with people who didn’t understand him.

ISOBEL I’m really angry sometimes because Harry doesn’t let me in the games room and when I want to go in sometimes he fights me and kicks me out. Also, Freddie makes the room too loud which makes my head hurt and he won’t share things which also makes me sad because he hits me when I try and take a sweet.

Did it also affect things in a positive way too?

ADAM I have worked as a support worker for nearly three years, I spent two summers working at a summer camp for people with disabilities in the United States, and I am now studying my Post-Graduate degree in Autism Studies. I would never have gone to America if it wasn’t for Matthew, nor would I be studying my degree in autism now. Learning more about autism has led me to have so many amazing experiences around the world – and Matthew has been my inspiration through all of this time.

BEN We get to go to the front of queues at theme parks and go on the plane first when we go on holiday!

MATHILDA I think it has made me considerably more self-aware and socially aware. I am perhaps overly concerned with people’s safety and well-being, and I feel this is a direct result of growing up with my brother. I also now work professionally with autistic students at university, a job that I love, which I wouldn’t necessarily be doing otherwise. I also have a children’s book that is being published next year about a brother and autistic sister, which obviously wouldn’t have been possible without my experience!

ASHLEIGH His uniqueness is probably a really big positive.



Adam is 26 and lives in Manchester. His brother Matthew is 23.

“Matthew is a diagnosed with autism (what was Asperger’s) and Tourette’s. He is on the higher functioning end of the autism spectrum and can verbalise and communicate well. He attended a mainstream school and now lives in residential care (Tuesday-Sunday) and at home (Sunday-Tuesday)”.



Ashleigh is 16 and from Runcorn. Her brother Patrick is 17.

“Patrick is now mainstream after years of SEND provision. Patrick is verbal, with a large vocabulary of sassy comebacks! Although he’s very confident, socialising can be difficult but his step into acting has helped with this. We live in the same house, in next door bedrooms.”



Isobel is 7 and lives in Cheshire with Harry who is 8 and Freddie who is 5.

Both Harry and Freddie have autism. Harry is in a mainstream school, can talk fine, is really good at playing games but he struggles to control his anger. Freddie is really good at making loud noises and wrecking things. He struggles when mummy goes because he cries lots, so I make him happy. He cannot talk apart from counting and colours. He does use sign language and has pictures to ask us for things. He goes to a special school.

ISOBEL The best things are that they make me laugh lots even though they fight me lots. Also it means I don’t have to share a bedroom with either of them which is great.

What have you been able to help your sibling with?

ADAM I try to help Matthew think about his autism in a much more positive way – and focus on all his amazing attributes! I also often try to explain to him why sometimes his way of communicating may not be the same as someone else’s.

BEN Mum says I helped Harry learn to talk because I am a chatterbox.

ISOBEL I’ve been able to help them be happy and to make them laugh by entertaining them. I’ve been helping Freddie to learn to talk and I’ve learnt some sign language with him.

What has been the most powerful lesson you’ve learnt through having a sibling with autism?

ADAM It’s been through this experience that I’ve really learned that things perceived as negatives really can be turned into huge positives. Autism was something that brought a lot of sadness to my life in the beginning, but eight years later and it fills my life with positivity.

BEN Everyone is unique and life can be lived in different ways.

MATHILDA To acknowledge myself as an important part of my sibling’s life.

ISOBEL That I need to understand that they need to be in control and have alone time and not to mess with them.

What do you love most about your sibling?

ADAM I love his care and compassion for those around him. The best part about Matthew is his goodness and his honesty – he has a very pure nature and loves to interact with people. I think if everyone had his openness and love, the world would be a much better place.

BEN He’s my brother and he makes me laugh.

MATHILDA His voice.

ASHLEIGH That even when we’ve spent time apart as soon as we’re together it’s like we’ve never been a part, we non stop laugh!

ISOBEL What I love about Harry the most is that he plays with me at night when we make funny noises with cups. The thing I love most about Freddie is that he plays with me and we chase each other and watch funny things together.

What has your experience taught you about yourself?

ADAM It’s taught me that difficult challenges in life can inspire you to achieve things that you didn’t think yourself capable of. Also, that we must focus on the great attributes that someone has, and not worry about the things that they don’t have.

BEN To try to be patient with people.

ASHLEIGH That I’m quite possibly on the spectrum myself!

ISOBEL I’ve learnt that I am a patient person who is very good at looking after people.

Knowing what you know now, what would you say to a younger version of yourself?

ADAM I’d tell him that things are going to be okay. I’d tell him that the frustration and pain that he feels inside will one day turn into his inspiration for his career, studies and life. I’d tell him to go and spend time with Matthew – to laugh, go have fun and enjoy every single moment that you are together.

BEN Keep calm and don’t over-react.

MATHILDA Talk to mum and dad, they want to hear and will listen.

As someone who is deeply connected with autism, what message would you like to send everyone else?

ADAM The more I spend time with people who have autism, the less I see any ‘disability’ and the more I see all the wonderful abilities that uniquely lie inside each and every individual.

BEN Autism is just a way of life that’s different.

ASHLEIGH Equal opportunities! Patrick’s not had the same opportunities as me and that’s been really difficult.

ISOBEL That everybody needs to understand that people with autism feel differently and think differently and you need to understand that they don’t act the same as us either. Sometimes they need their alone time and to just leave them and not expect them to look at you. Also to be kind to them because they can’t all talk but they do understand stuff sometimes.

MATHILDA Always presume competence, and listen first and foremost to autistic voices.



The Last Word

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



The Book to Go with the Mag!

You readers are a very loyal bunch so I thought you deserved to hear the story behind my new book *15 Things They Forgot To Tell You About Autism*, out this month.

I'll let you into a secret. It's not really 15 Things, it's a lot more. Bobby calls it 15 THINGS YOU TOTALLY MISSED ABOUT AUTISM!! but the thing is, you'd be forgiven for missing them. Noone tells you what it's important to know. You sort of find out the hard way. That is, with time and effort and sometimes a few tears.

15 Things...is the sort of book that I could only write having amassed a decent body of evidence from my own experience of raising twins. It's now 12 years since they were diagnosed and I'm one of those parents who can look back with the benefit of hindsight and tell myself where I went wrong. That's no fun at all, so I thought that I'd prefer instead to tell those at the beginning of this learning curve where they can go *right*.

I'm hoping that people will finish the book and go away with a couple of insights that will shape their views. The first is that you can't change a diagnosis, but you can shape your reaction to it. Having done that myself, I have found positive thinking the key to living in harmony with autism and I think it's the thing that has underpinned all our progress from the

moment we realised that our twins' brains were wired differently.

The second is a point that I'm very fond of making. Autism is not a solid brick, although it seems that way when a diagnosis is handed over. Someone's autism changes shape according to their interactions with the environment. Other people are a big part of the environment and so it follows that with some decent strategies and a good understanding of their experiences and difficulties, coupled with a calm disposition (most of the time!) parents – who are central to a young person's world - can really help a child with autism to thrive.

What frustrated me when the twins were younger was the idea that a solution was out there, but no one was telling us. There is no big secret. There are simply a large number of small solutions and after many years of putting those strategies into place, I've seen first-hand how they can make all the difference. Sometimes, though, you have to wait a while before you see the benefit.

This book isn't designed to be p-faced or patronising. God, I hope not. As I wrote in the introduction, humour is my trusty sword and I use it within those pages to axe through the traditional jargon and mythology that surrounds autism and to clear a path for others to tread along.

I hope that above all, 15 Things becomes a celebration of autism and a battle cry for parents everywhere to bring their kids out into the open without fear, shame or embarrassment. The more the world sees of autistic people, the more they'll learn not only to accept it, but also to celebrate it.

Oh and if you read my book and you like it, pretty please with blue flowers all around it and little white doves too, could you review it on Amazon? I'd be really grateful if it wasn't just my mother doing this.

If you're local do come to the launch: Waterstones Deansgate, April 24th, 6.30pm. Drinks, nibbles and book signing. Sign up by emailing manchester@waterstones.com. Buy your copy at www.jkp.com or on Amazon.



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