



Aukids®

Issue 46
Jan/Feb 2020

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separately

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

For Parents and Carers of Children with Autism Spectrum Conditions



No place like home
What's it like
swapping school for
home education?



Walkie Talkie
'My grandson won't
keep still while
we're speaking!'

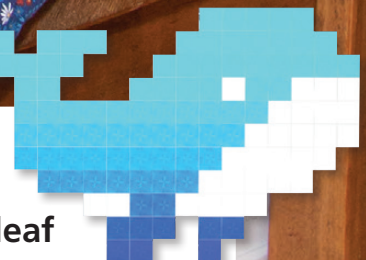


Step by Step...
Joshua Levine's
simple guide to
giving instructions



PLUS

WIN A Nanoleaf
Canvas Smarter
lighting kit worth £179.99!



Letter from the Editors

Happy
New Year,
readers!



As you can see below, we already have plans for 2020. AuKids is holding its first ever one-day event designed to help parents and carers on a large range of issues. Co-founder of AuKids, Debby Elley, will be giving a humorous and valuable whistle-stop tour through as many easy and beneficial parenting strategies that she can get through in under an hour! Some of them are detailed in her book *15 Things They Forgot to Tell You About Autism* and some are for your ears only!

The Ice Cream Sundae Guide to Autism is definitely our most popular ever feature and you'll have a rare chance to hear about the creation of the idea from both your founders Debby and Tori, including what informed its creation and how it works when you're explaining autism to both adults and children. Autism is

very complex, and a challenge to explain in simple terms. Yet that's what you're obliged to do in order to help others to help your children.

The editors' new book for children by the same title will have been launched just a few weeks before the event, so be the first to get one!

Tim Tuff is our autism advocate. Ten years after joining the AuKids team, Tim now has fantastic confidence when presenting his highly insightful talk on how autism feels to him. Tim explains how his brain responds to difficulties such as changes in routine and sensory issues, those factors that cause anxiety and strategies that calm him. With positivity and a great deal of charm, he inspires every audience who hears him and is happy to take questions.

As well as running the agency Time Specialist Support Ltd, AuKids other founder, Tori Houghton, is trained as a speech and language therapist. Her experiences in working with 'hard to reach' children have informed many articles in AuKids. Now you'll have a chance to hear some of Tori's 'breakthrough' moments that made her so successful when working with autistic children and their parents.

Don't delay in signing up, places are very limited. As usual, the money raised from the event will help to pay for magazine production this year.

We've got plenty to get stuck into this issue, but perhaps the most interesting for us was hearing from other parents about their experiences of home educating their children. What our home educators seem to value the

most is the ability to be flexible with their children and follow their interests. We hope that the article will act as encouragement to those parents already considering home education as well as informing education settings about the sorts of approaches that are needed in order to adapt.

Our archive piece is one of our favourites – Saying 'No' Without the Volcano. Keeping boundaries without explosions is a tough one, and this feature was hugely popular when we first printed it.

A quick word regarding our website at www.aukids.co.uk – we have put a small donation fee of £2.00 on recent download issues for this year. If you need to know more about one of our magazines just contact us at aukidsmag@gmail.com

Tori & Debby

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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 **periscopestudios**

www.periscopestudios.co.uk

Aukids brings you...

The Real Autism Show

Answers to real-life questions, from the team who've lived it!

For 11 years, AuKids has been providing you with practical, easy advice on how to get the best for your children. Now, for the first time, the team comes together in an intimate setting to bring you their best advice face to face.

Venue: Cheadle Town Football Club, Park Road, Cheadle SK8 2AN

Talks include:

- **How to Explain Autism With Ease!** – Debby Elley & Tori Houghton
- **Strategies for Parenting Brilliance** – Debby Elley
- **Jam on a Marmalade Day: Autism from the Inside** – Tim Tuff, adult with autism
- **Creating Communication** – Workshop with Tori Houghton, speech and language therapist

Browse and buy past issues at our lunchtime stall. This is your FIRST opportunity to get a signed copy of the team's BRAND NEW ground-breaking children's book *The Ice Cream Sundae Guide to Autism*, with colour illustrations from AuKids' graphic designer Jo Perry.

Price: We are a social enterprise. Your entrance fee of £25 will help to pay for magazine production in 2020. Includes drinks and refreshments; bring your own lunch.

Book at:
<https://aukidsrealautismshow.eventbrite.co.uk>

Save
the date!
July 9th 2020
10am-2.30pm

PLACES ARE LIMITED – BOOK EARLY!

AUKIDS TESTERS NEEDED!

Alain Perrault's son Zeb has autism and ADHD and is non-verbal. One day he opened the front door, ran across a busy main road and disappeared. Luckily for the family, their neighbour spotted him on her way back from shopping and brought him back home.

Anxious not to have a repeat incident, Alain and his wife started to search for safety devices that would be within their budget but couldn't find anything suitable.

After winning a social enterprise grant from UNLTD, they created their own emergency device for vulnerable people and 1Life Emergency Service was the result.

How does it work?

1life stocks a variety of wearable jewellery and other accessories, such as cards and keyrings. All of them carry a QR code plus unique security code, number to text and an emergency web address linked to a secure online profile.

These accessories are also NFC enabled. NFC stands for Near Field Communication; this means that if someone finds your child wearing an accessory, they can tap it with their mobile phone and be linked instantly to your online emergency security page. But don't worry, if the person who responds to the emergency doesn't have their mobile set up to accept NFC, they can still access the wearer's details using the unique code plus the QR code, text number or website details printed on the item.

Once you register with the service (which is free) you can put as little or as much information on a child's online profile as you wish to be available in an

emergency, including details of care providers. If you have more than one person needing this service in the family, you can create multiple profiles and then your purchases can be linked to them.

How do you get started?

Buy an accessory and create an account, then create a profile for your child and add as much information as you like. You then add the security code that came with the item to your child's profile and that's it!

Are you ready to test this for FREE?

Alain is looking for 15 customers to trial the accessories and to give feedback on his website. This means a bunch of lucky AuKids readers get to order a free accessory! All you have to do is register at www.1life.today, using the promotion code **Aukids15**, but hurry as it's first come first served! Once you've done this, if you're successful, Alain will send you a questionnaire to complete – and you get to keep the jewellery/accessory you order.

If you'd rather not answer a questionnaire, you can still benefit from a discount on anything you buy at 1life, just use the promotion code **Aukids20** for a 20% discount on all orders up until February 29th 2020.

For more information, and to see demonstrations on how to sign up, go to www.1life.today



Your New Travel Companion



As parents of a fabulous son, Archie, who was diagnosed with autism at the age of four, Devon-based Paul and Nicola Owens decided from day one that their travels and passion for always moving forward would not stop...

"As we all know, having a loved one on the spectrum has its own special path," Paul told AuKids. "Our new Atrip Hub at www.atrip.world is a website for the autism community to share, review and recommend suitable things to do, whether it's a lovely country pub for a bite to eat or a cinema in the heart of the city, a family attraction or a special place of interest, museum or country gardens. Travel is within human nature

and Atrip should help our autism community to help ourselves by making autism-friendly recommendations."

It's completely free to list your business or organization and it's free to register and review.

So jump on board and start sharing your experiences!



Cover Star

- Name** Bronwyn Wilson
- Age** 10, recently diagnosed with autism.
- Lives** Dukinfield in Tameside
- School** Godley Primary Academy.
- Likes** Singing, dancing, reading, acting and Harry Potter. She loves learning and going to school.
- Dislikes** People when they are being annoying (her words) and celery.

Bronwyn enjoys the structure of school and is doing very well. She is hoping to get a place at The Blue Coat School in Oldham for her secondary education. She liked it there because it's strict and the building looks like



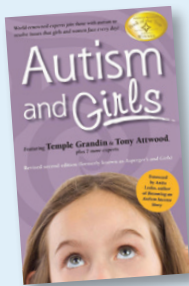
Hogwarts. Outside of school, Bronwyn attends NK Theatre Arts in Romiley where she enjoys drama and musical theatre and she attends dance lessons at ARTSync in Hyde.

Bronwyn has just been cast as Jane Banks in a Mary Poppins extract in Magic of the Musicala junior at Romiley Form with NK Theatre Arts, a highly inclusive theatre company. It's her first solo part and she's delighted.

LEADERS LIST IS OUT!

The 2019 Learning Disability and Autism Leaders List was published last month, created as a partnership between Learning Disability England, VODG and Dimensions. Over 40 new people and groups, including a number of people with profound and multiple learning disabilities, were selected by 18 judges to be named on the list. Their extraordinary contributions towards making society a better place are detailed at www.dimensions-uk.org

Reviews & Prizes



BOOK

Autism and Girls

Featuring Temple Grandin, Tony Attwood plus 7 other experts

Published by Future Horizons
£19.50
ISBN 9781941765234

When I saw the cover of *Autism and Girls*, I looked forward to getting stuck in. I mean, what's not to love about a book with Temple Grandin and Tony Attwood's names on the cover? It looked amazing and it definitely doesn't disappoint.

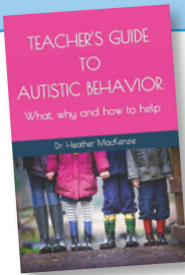
In some ways, Tony and Temple's articles are not the most informative here – those of us who have been wading through life with autism for a while have already been reading their work with interest if not desperation (this time Tony shares his views on camouflaging in autistic girls and Temple speaks of the importance of her career to her identity).

For me, the really interesting chapters were on those things that had never occurred to me. How might a woman with autism experience maternal 'instinct'? How do we help girls and women with autism disclose abuse or assault when traditional counselling doesn't fit their natural communication styles? And – particularly for me as mum to an eleven-year-old autistic daughter – how on earth do we navigate the massive issues thrown up by puberty?

One benefit of having chapters by different authors is that you don't have to read all the essays in the book at once, or in any particular order - you can pick whatever feels most useful to you. The variety of authors means that all the essays are subjective and it's okay to take some parts and leave others if they don't apply to you or your daughter (or other autistic women you know).

If I had to choose one word to describe this collection of essays it would be 'equipping'. Much of the writing is to do with preparation; as a mum daunted by the complications high school will undoubtedly throw up, this is a comforting book. I would absolutely recommend it - whether you have been navigating autism for a while or whether it's all new to you, there's something for everyone.

By Abbie Robson, AuKids reader



BOOK

Teacher's Guide to Autistic Behaviour

By Dr Heather MacKenzie
Published by Wired Fox Publications
£13.53
ISBN 9780968446690

Many of you will know Dr Heather MacKenzie, a Canadian Speech and Language Pathologist, as one of our expert panellists. I'm so glad that she has written this short and accessible guide for teachers. It contains heaps of the author's trademark wisdom - strategies that I've really benefited from myself over the years.

Heather has a great understanding of all the factors contributing to what we know as autistic behaviour. In addition, crucially, she has also shares how we can overcome some key difficulties at school simply by adapting our own approaches. She isn't purely focusing on troubles relating to behaviour, but also on education difficulties caused by a compromised set of executive functioning skills. Got a child who finds it hard to stay on task? Haven't we all! She'll explain why.

Executive functioning skills are part of self-regulation and the other difficulty our kids face at school is that their ability to self-regulate - already a challenge - is further stretched by common methods of teaching

and aspects of the school environment.

The book moves on to explain specific stressors in school, with a chart of approaches that can create stress and examples of how that anxiety could manifest itself in autistic children. Key offenders are vague instructions, unclear expectations and sudden changes, but there are a lot more.

Having given a thorough explanation of the barriers to learning, Chapter 5 of this pocket guide covers some simple solutions. Heather advocates developing self-regulation by starting with an awareness of what's happening in your own body – many of her strategies involve helping children with autism to connect their emotional and physical states. There's some great pointers on useful apps for mindfulness and mindful breathing. Later the chapter includes other ideas for helping children with self-regulation. Her approach helps children to absorb those ideas without feeling judged or pressurised.

Later, the book gets into tackling specific difficulties using a variety of tools – the language that Heather uses is key. Step by step advice includes a great guide to writing Social Stories™, too.

Any teacher or teaching assistant reading the 56 pages of this pocket book will be better armed to face the day ahead.

By Debby Elley, co-editor AuKids



BOOK

Inclusive Education for Autistic Children

By Dr Rebecca Wood
Published by Jessica Kingsley
£16.99
ISBN 9781785923210

I was keen to read this book as I have worked in education for 14 years, mainly as an English teacher, and my autistic son is due to start secondary school next year. It is a book that feels positive and empowering, though at times it made me angry to read how current school environments, curriculum and interventions can be unnecessarily problematic for some children.

Dr Wood begins by introducing eight autistic contributors, ranging from eight years-old to adults, and there are many quotes and comments from them throughout. The book is written in an academic style and it is not a light read; however, the contributions from these autistic people are engaging and enlightening and for me really lifted the book. Dr Wood draws together many studies, perspectives and opinions on autism and

there is an extensive bibliography.

This publication is mainly aimed at teachers and those working within education but has plenty of relevance for parents of school-aged children who want to understand more about how schools 'include' (or not) autistic children. There are ten chapters covering various aspects of school such as sensory issues and classroom support. I warmed to the author, who is a former teacher and has an autistic child. The book is based on her PhD.

Rather than giving prescribed strategies for autism at the end of each chapter, the author steers in the form of 'key points'. The book therefore is less about specific strategies and more about widening knowledge and shaping attitudes in a positive way. There is a message throughout that a strong working relationship between an autistic child and their teacher can and does have positive outcomes.

In conclusion, a useful read for those working in education and for parents. I would love to lend the book to my son's class teacher.

Cara Salway
Aukids reader, parent and English teacher



BOOK

The Parents' Guide to Managing Anxiety in Children with Autism

By Raelene Dundon

Published by Jessica Kingsley

£12.99

ISBN 9781785926556

This is the third brilliant book by Raelene Dundon that I've reviewed. In fact, I liked it so much that I contributed some effusive blurb for the jacket. Why? The author's wisdom is always infused with a real understanding of autism as it's lived, partly due to her many years as a psychologist and partly because two of her children have autism. In addition, she has a refreshing plain-speaking style and the ability to give real-world solutions without being patronising. All this while avoiding jargon. Yep, she's my kind of writer.

I'm glad Raelene poised her straight-talking pen over the subject of anxiety. It's one of the most troublesome side dishes of autism because it causes so much distress, both for the child experiencing it and the parent witnessing it. Tackling anxiety should, I believe, take centre stage early on in our children's lives if we're to support them with the tools they'll need to navigate adulthood.

The guide begins by explaining why anxiety is prevalent in autism and identifying some common triggers. When anxiety strikes, there's such a variation in our children's behaviour (from internalising it to full-on aggression) that Raelene takes time to describe different responses using small case studies. By Chapter 4, she's focusing on the signs that help is needed, before moving onto the more practical side of the book in Part 2. There, you'll find a wealth of strategies to help children to develop awareness and understanding of their own emotions. The author also focuses wisely

on methods to achieve physical and mental calm and shares ideas on alleviating sensory distress, too.

I particularly enjoyed the next section, in which Raelene lists common ineffective strategies used by parents to tackle anxiety before suggesting more positive approaches instead.

Chapter 7 onwards deals with specific kinds of anxiety including social anxiety, phobias and generalised anxiety. I felt that the omission of OCD (Obsessive Compulsive Disorder) was an oversight, but there's a well-researched chapter on PDA (Pathological Demand Avoidance).

For some of you, Part 3 will be the most helpful, as it tackles explaining anxiety to others, particularly teachers. It opens with that accusation familiar to many: 'They are fine at school, it must be something that is happening at home,' and suggests how you can help education professionals to better support your child.

As the book nears its close there's a guide to professional interventions and a small mention of medication, though this is by no means a focus.

It rounds off with a generous amount of recommended children's literature on anxiety, as well as a photocopyable anxiety chart to help you note patterns and solutions. Talk about thorough!

If I could choose ten books only for an autism shelf, this would be one of them.

By Debby Elley, co-editor
AuKids

Light up Your Life with Our Nanoleaf Comp!

Oooh you are in for a treat. The Nanoleaf Canvas is an interactive lighting system that's awesomely versatile. With nine modular panels per pack, you slot them together in whatever pattern you want (it's the easiest possible jigsaw). Then, the lightweight panels stick easily to walls or ceiling with the mounting tape supplied.

Next comes the fun part. You can operate Nanoleaf Canvas panels a number of ways – by touching them, through the control square, with your voice or through the Nanoleaf App (for Apple devices).

There are 16 million colours and all shades of white to select. You won't be bored. Set it to neutral colours for functional lighting, then have some fun with the settings to create changing colour 'scenes'. With Nanoleaf you can touch the lights themselves to control, 'paint' and play games.

New to Nanoleaf is the 'music visualiser' mode. Once you've activated rhythm mode, you can watch your favourite music transformed into visuals.

We've tried it. It's a truly brilliant gadget.

You can even have it interacting with Alexa, Google Assistant or Siri.

For us, this is the ultimate sensory toy, only without the ultimate price tag.

The company was kind enough to donate a Nanoleaf Canvas to Everyone Can inclusive gaming

centre in Sale, Cheshire; the charity has just built a new sensory room.

Nicola Jones there said: "We were easily able to create the shape we wanted to suit our sensory room. To stick with our gaming theme, we went for a Pacman ghost! So far, the children who use our centre absolutely love it. When some of them have felt a bit overwhelmed it has really calmed them down being in the room and watching the Nanoleaf canvas. It looks fabulous and has had a huge positive impact on the children here!"

To cap it all there's free delivery and free technical support if like us you tend to be a bit of a thickie when it comes to working fantabulous new technology.

Want one, worth £179.99 all to yourself? Just answer this question.

Q: Look closely at the picture in this competition or you can find it at www.nanoleaf.me The family using Nanoleaf Canvas in this picture is having a whale of a time. But what time is that?

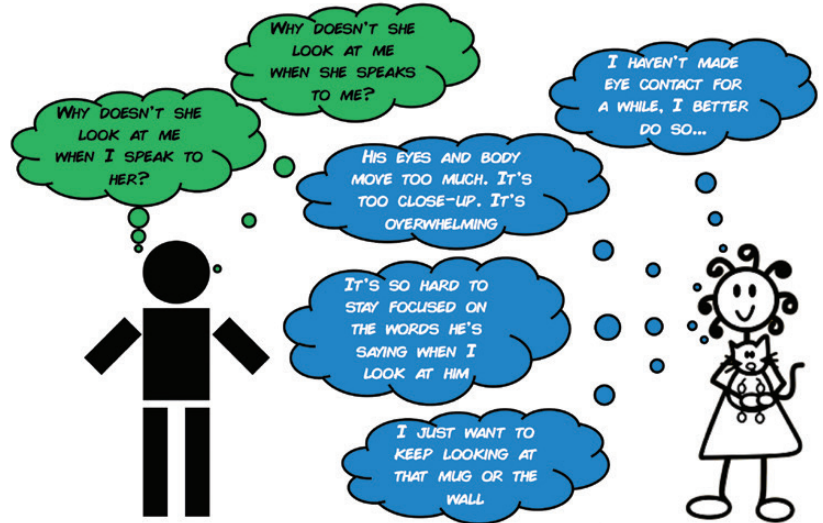
Send your answers to us no later than February 29th by emailing auidsmag@gmail.com with NANOLEAF in the subject header. Be sure to include your full name and address.

By entering you agree to us passing your details to Nanoleaf purely so that they can send you your prize. No other third parties will be notified of them. No cash alternative.





“ My 13 year-old grandson is an able boy doing generally well in mainstream. Generally he is quite sociable but he has one behaviour that is annoying to both family and teaching staff and we are not sure how to deal with this. When talking to you he wanders around and seems unable to face the person he is speaking to. ”



Debby Elley

Co-editor of AuKids magazine

In autism, auditory language processing is difficult. Standing still and processing your facial expression and your body language as well as the words you are saying can be absolutely overwhelming.

So your grandson isn't trying to be rude, although socially it may appear a bit odd. What he's doing is trying his best to process what you're saying. He's doing this by cutting off other avenues of information (e.g. visual) which cuts down on confusion, and I suspect the moving around may be something he does to self-regulate and prevent his anxiety from becoming too high when he is processing. And much like fiddling with a pen during a long meeting, it may help him to focus as well.

What his body is doing is clever - it is keeping him self-regulated enough to listen to you without getting

overwhelmed. Unfortunately that also has the effect of making it appear as if he is not paying attention. But he is! Alec, my non-verbal son, looks away when he is listening to you and I can think of many others who do the same. He has to 'switch off' one channel.

Some autistic people also find it physically quite painful to look at people's faces, the information from other people's eyes can be too much for them. One thing that some autistic people are taught is to look at someone's forehead so it appears you are listening (at the point between their eyes).

I'll leave it to our occupational therapist to talk about the moving about bit, but it might be that something to fiddle with could be a viable alternative to pacing. Whatever you do though, don't say 'Keep still and look at me!' This is hard enough.

This is also one of those things - if people around the autistic person understand WHY their behaviour is like it is, it needn't be a problem. You may like to ask him to experiment what helps him to best focus when people are talking to him. I've found asking without judgement to be very helpful with my own verbal son, he comes up with some surprising answers about how his experience differs to my own.



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

Debby, that's a lovely explanation. It's right on. I'd like to focus more on what to do about it.

It's odd behaviour that's sure to make him stick out and may very well alienate other people. I'm uncomfortable just explaining it to people as part of autism. I'm more comfortable finding a strategy he can use that he's okay with and which wouldn't make other people think he's weird.

I think it's excellent advice to ask the young man about it. It would be helpful for him to view it for himself (as in a video) and see what he thinks. This, of course, has to be presented in a positive

way - "I noticed that sometimes your body starts moving around when you're talking with other people. That makes it really hard to chat." Then, I'd ask: "What can you do to help yourself?"

He needs strategies that are (1) autism sensitive, (2) developmentally appropriate, and (3) culturally aligned. So ... some compromise needs to be reached amongst what he can tolerate from processing and sensory points of view, what his peers do (they're typically not all that great at eye contact), and what's appropriate to his family and school culture. I believe all three of these threads need to come together.

He's a male and a teenager. Have you ever noticed how most 'guys' stand in parallel talking to each other? They often line up, back to a wall or seated beside each other, and talk while looking straight ahead, only occasionally glancing at each other. That's a compromise that could be reached with this young man. I often prompt autistic teens and adults to just look at the other person's face (not eyes) every so often "to make sure they haven't gone away" - that tends to be an explanation that carries some weight. Having him 'station' himself (on a wall or piece of furniture) likely will help him keep his body more still. The wandering around really has to be reduced because it would be quite off-putting to others. I'm sure the OT will have other suggestions for helping with the movement side of things.



Maura Campbell

Maura is a feature writer for Spectrum Women, an international online magazine for and by autistic women.

She was a contributing author for the book Spectrum Women - Walking to the Beat of Autism and one of three authors of the forthcoming *Spectrum Women - Autistic Parenting*, to be published by Jessica Kingsley this year.

Looking directly into someone's eyes feels incredibly intense to me and, unless it's someone with whom I'm in an intimate and loving relationship, it makes me extremely uncomfortable. It's as though the other person is looking directly into my soul, seeing my innermost thoughts, judging me and finding me wanting. It feels unnatural and puts my brain on high alert, which means I'm having to battle with the 'fight or flight' instinct, making it nigh on impossible to concentrate on anything else. I'm literally like a deer in headlights.

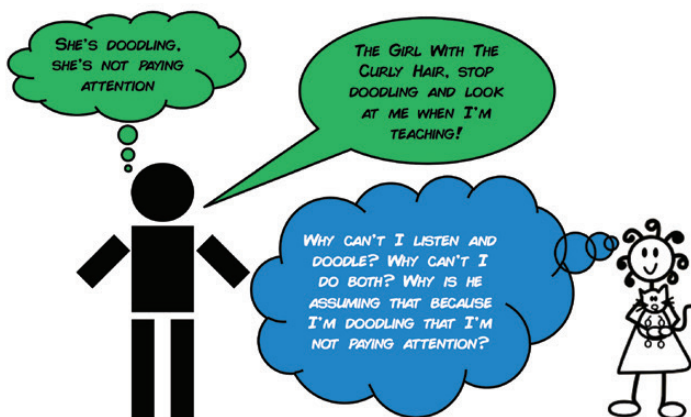
All of this takes a lot of conscious effort, of course, and as Debby says makes it harder to process what the other person is actually saying. As John Elder Robison, author of *Look Me in the Eye* puts it, 'I don't really

understand why it's considered normal to stare at someone's eyeballs.

I've trained myself to look at the bridge of someone's nose, which makes it seem to them as though you're looking at them, and to look away occasionally rather than staring fixedly at their face. Gary Numan says he counts to five in his head when making eye contact during interviews then looks away, then back again for five seconds and away and so on, since he read that five seconds was the appropriate level of eye contact to give someone. Imagine having to do all of that with a camera in your face while at the same time trying to process interview questions and think about what you want to say about your latest hit album!

I also find it much easier to have a conversation with someone if we're sitting or walking side by side or engaged in an activity together, and I've noticed that this approach works well for my autistic son as well, who's nearly the same age as your grandson. Autistic people are better able to open up when we don't feel as though there is a massive spotlight shining on us.

Communication can take many forms and I would suggest the priority here should be to make your grandson feel that he can always express his needs, wants and feelings to his family and teaching staff without judgement. Allowing him to communicate in a manner that feels 'right' to him, even though it may seem unusual to you, will build trust and help him feel accepted, valued and understood.



I LIKE TO LOOK AT SOMETHING NEUTRAL, THAT DOESN'T MOVE, OR SOMETHING FAR AWAY IN THE BACKGROUND. IT HELPS ME TO CONCENTRATE.

Illustrations courtesy of The Girl with Curly Hair www.thegirlwiththecurlyhair.co.uk

At the Together Trust, we deliver individual care, support and education services across the North West.

Every year we support thousands of children, young people and adults to lead **happy, fulfilled lives.**

To find out how we can help you visit togethertrust.org.uk

TOGETHER TRUST

Registered charity number 209782



Lucy Griffiths

Lucy is an Occupational Therapist and Sensory Integration Practitioner at the Seashell Trust. The charity incorporates a school, college and residential care for children and young people with complex and severe learning disabilities.

www.seashelltrust.org.uk

I would concentrate first on your grandson's need for movement, before looking at the reasons for reduced eye contact.

It sounds like he is needing to move to concentrate and focus on the conversation. By moving and stimulating what is called his vestibular system, he is gaining feedback about his posture, balance and positioning all helping to regulate his level of alertness.

Your grandson may struggle

with registration, which is how he responds or attends to sensory information. He may also have difficulty with auditory processing which would mean that he might struggle to attend to what you are saying amongst other background noise. Therefore, by moving, he is keeping himself more alert and able to focus on what is being said.

You could support your grandson by ensuring that he has regular opportunities for movement including activities that cause his head to be upside down or rotate, for example yoga or using a swing. There are lots of ways in which he could help out around the house as well, which could be beneficial.

When trying to engage him in conversation, state his name clearly first to ensure that you have his attention. Keep the environment quiet and calm for more important conversation, so that he can filter out extraneous noise more easily and focus on you. He could even try an inflatable movement cushion that would allow him to sit but gain some movement and increased sensory input, without moving around the room.

Further Info

Website: Griffin Occupational Therapy have published some great advice on choosing sensory seating for those who have difficulty in keeping still here: www.griffinot.com/sensory-seating-seeker/

Buying stuff: Try www.multi-sensoryworld.co.uk for vibrating cushions and www.exploreyoursenses.co.uk for weighted objects that 'centre' fidgeting kids and textured air cushions.



A JOB WELL DONE!

We like to encourage our kids to problem solve. There are, however, times when you do need to give your child instructions.

Dr. Josh Levine is from Florida, USA, and has been coaching families of children with autism since 2000. He is a Board Certified Behavior* Analyst, the Clinical Director at The Sonder Academy, and creator of the very first Do-It-Yourself Applied Behavior Analysis (DIY-ABA®) home system. You can contact Dr. Josh at admin@drjoshlevine.com.

Here's one of Josh's simple step by step guides on giving instructions in a way that autistic children can process, with a little AuKids magic thrown-in!



ONLY GIVE INSTRUCTIONS THAT YOU ARE ABLE TO FOLLOW THROUGH. FOR INSTANCE, AVOID 'HALF AN HOUR ON YOUR HOMEWORK NOW PLEASE!' IF YOU KNOW THAT THE CHANCES OF THEM ACHIEVING THIS ARE ABOUT AS HIGH AS YOU PLAYING IN THE WORLD CUP SQUAD. AIMING HIGH ISN'T GOING TO WORK HERE - KEEP IT LITERAL.



DON'T GIVE ANY INSTRUCTIONS FROM ACROSS A ROOM. AUTISTIC KIDS HAVE DIFFICULTY ORIENTATING TOWARDS AND PROCESSING YOUR INSTRUCTIONS, THEY NEED ANY BARRIERS REMOVED TO HELP THEM.



USE PHYSICAL GUIDANCE AND FADE IT. 'FADING' IS WHEN YOU START OFF BY PHYSICALLY HELPING A LOT, THEN GRADUALLY REDUCE YOUR HELP ON THE EASIER PARTS OF A TASK, UNTIL YOU'VE REDUCED IT TO NOTHING. EVENTUALLY ONLY VERBAL ENCOURAGEMENT (OR PICTURE GUIDANCE) IS NEEDED. THIS REQUIRES PATIENCE AND LONG PAUSES!



ENSURE YOUR CHILD IS ORIENTATED TOWARDS YOU BEFORE GIVING INSTRUCTIONS (NOT NECESSARILY LOOKING AT YOU, BUT ATTENTIVE). REMOVE DISTRACTIONS LIKE TV, IPAD, COMPUTER GAMES AND ANY LOUD NOISES BEFORE GIVING INSTRUCTIONS. GIVE YOUR CHILD LENGTHY WARNINGS BEFORE THEY HAVE TO SWITCH OFF ANYTHING, OTHERWISE THEY'LL BE TOO BUSY HAVING A MELTDOWN TO LISTEN!

5



GIVE ONE INSTRUCTION AT A TIME: DON'T REPEAT THEM. MAKE THE INSTRUCTION DIRECT, CLEAR AND CONCISE. DO NOT PROVIDE ANOTHER INSTRUCTION UNTIL THE FIRST ONE IS COMPLETE. E.G. "PLEASE FIND YOUR SCHOOL BAG. NOW, LET'S LOOK FOR YOUR HOMEWORK TOGETHER". AUTISTIC CHILDREN CAN FIND IT HARD TO RECALL MORE THAN ONE INSTRUCTION.

6



GIVE PRAISE FOR FOLLOWING DIRECTIONS, HOWEVER SMALL. LET YOUR CHILD KNOW EACH TIME HOW MUCH YOU **LOVE IT** WHEN THEY ARE ABLE TO FOLLOW AN INSTRUCTION. REMEMBER YOU NEED TO TAILOR PRAISE FOR YOUR CHILD - SOME LIKE A BIG FUSS, SOME PREFER A LOW-KEY 'HIGH FIVE!'

7

FIRST PUT YOUR SHOES ON, THEN WE CAN GO AND SEE THE FILM

USE FIRST-THEN STATEMENTS OR IMAGES. THIS REINFORCES THE REASON BEHIND INSTRUCTIONS AS WELL AS BUILDING MOTIVATION TO FOLLOW THEM.

8



FIRST



THEN

YOU CAN USE FIRST-THEN FOR NON-VERBAL CHILDREN, TOO, BY HAVING A SIMPLE BOARD WITH VELCRO PATCHES FOR SYMBOLS TO STICK ON. YOU CAN EVEN DRAW IMAGES ONTO WIPE-OFF BOARDS ABOUT WHAT'S HAPPENING NEXT.

9

I'D RATHER MAKE MY BED

PROVIDE OPTIONS, FOR EXAMPLE: "WHICH JOB WOULD YOU PREFER TO DO? WOULD YOU PREFER TO EMPTY YOUR RUBBISH BIN, OR MAKE YOUR BED?" AUTISTIC CHILDREN FOLLOW DIRECTIONS BETTER WHEN THEY HAVE AN ELEMENT OF CONTROL.

10

WE CAN DO IT!

LEARNING TO FOLLOW INSTRUCTIONS HELPS AUTISTIC CHILDREN TO:

- BREAK DOWN A TASK
- BUILD CONFIDENCE AND SELF-ESTEEM
- MAKE CHOICES
- RESPOND BETTER TO INSTRUCTIONS AT SCHOOL

Saying "NO" Without the VOLCANO



Saying 'no' sounds simple, but in fact this two-letter word has many complex meanings. This is perhaps why kids in general can react badly to it. The difference is, where autistic children are concerned, such a simple request can result in one giant 'volcano'. It's easy to see why parents can be reluctant to say the 'N' word, but are we doing ourselves any favours?

Child psychologist Tanya Byron, famous for programmes such as *The House of Tiny Tearaways*, says:

"I think you should never avoid using the word 'no' out of fear of a child's reaction. If you are able to say it and assertively deal with the reaction, but not give in, fundamentally the child will know that 'no' means 'no' and no matter what they do, it won't make any difference."

Of course, saying 'no' and dealing with the consequences can be tough, but avoidance can create a rod for your own back as your child begins to realise that getting their own way is a breeze.

It's even worse if you try to hedge round the 'no' with vague reassurances about the request being met in the future. When that request isn't granted as promised, you break down valuable trust between parent and child and you may never get it back. So, our first piece of advice is not to make false promises just to keep the peace.

So, what do you do for an easy life?

THE PROBLEM WITH 'NO'

For an autistic child, there are several problems with the word 'no'. For a start, 'no' doesn't always mean 'no' even when applied to the same thing. In their

book *It Can Get Better* by Paul Dickinson and Liz Hannah, the authors point out that the unpredictability of the word is an issue with autistic kids.

'Sometimes they have something for a treat and at other times the treat is not available or not allowed. In these occasions it is very important to be consistent. Try to work out a strategy in advance and stick to it.'







The second problem with the word 'no' is that because it's quick and easy, it's often said in an impatient hurry, or shouted in a tone of voice that begs rebellion. 'No' becomes a brick wall. There's no explanation behind it and the only answer is to fight it.

In order to avoid a 'volcano', you need where possible (and it isn't always possible) to provide an answer that is easily understood and gives direction without being imprisoning.

Firstly, make it clear that you do understand what the child is asking. For a child who is learning to communicate through PECS or whose verbal communication isn't clear, their concern over whether you 'get it' or not can play a major part. You may have to repeat the request back to them: *'You want the Buzz Lightyear. I understand.'*

Secondly, ask yourself whether you really mean 'no' in the first place. There are only a few instances where 'no' is an absolute, usually when the child is about to cause themselves or others harm. If you only use it when it's really necessary, then you won't often have to deal with the hefty response it generates.

Here's a few examples of what 'no' can really mean, and what you could say instead to make life less confusing and frustrating for an autistic child.

When 'No' means...	What you could say instead to an autistic child (in a nice calm voice)
 Not now	You can have that at 4 o'clock (be specific and carry out your promise)
 It's dangerous – stop!	Stop what you're doing: that will hurt you
 You can't have it – (in a shop)	We have not got the money for that
 You can't have it – (it's full of additives and you'll bounce off the walls)	Mum doesn't like you to have that because...but we can have this instead.
 That's inappropriate	Tell them when it's OK to do it. If it's never OK, say 'that's not nice, people find it rude.'
 I don't know	I need to find out a bit more about that before I say 'yes' or 'no.'

You get the gist: always offer explanations, even if you feel you haven't the energy to, because you certainly won't have the energy for what's coming if you don't!

If one particular request often causes problems, you may like to prepare a Social Story™

(see Issue 15*) to fully explain what the situation is.

That may sound like a lot of hassle, but in the long run it can save time and energy. *'Remember when we wrote about this...?'* Drawing simple cartoons after an event to help a child gain more insight into a social situation is a lot more helpful than a quick 'no'. Again, a stitch in time here will save you nine...perhaps ten or eleven if you're lucky.

For an autistic child, an explanation, tailored to their understanding, is usually valuable. If wordy explanations aren't relevant in your case, then simple visuals and Makaton signs can provide an answer.

Liz Hannah says: "It is hard to have a generic symbol that will prevent a child feeling thwarted and angry when something is not allowed, but maybe it is possible to think of symbols to suit the situation. For example, a 'wait' card, a picture of a timer or a substitute favourite object."

Liz recalls that she used to take young autistic pupils shopping and they learned from a consistent routine that only things on the symbol shopping list were purchased. "There were a few tantrums early on until they'd



grasped the procedure, and that is the hard part. Learning takes time, but symbols and pictures work so well when used consistently with single words and short phrases that they are worth the effort involved, as they do away with anxiety and confusion and make life a little easier.”



headphones, grab a suitable alternative and make a swift exchange rather than just taking them away

- Use counting down and timers so that games aren't suddenly stopped
- Take a child off one track and put them on another
- A tip from Tanya - give lots of positive praise when the child does respond well to the word 'no'. Tell them you're proud of them for doing what they were told straight away and reward as necessary. This means they've got an incentive to be obedient - doing the right thing works, and gets a reaction that's even more rewarding than you losing your temper!

- Consistency is key



OTHER TIPS

- Try not to assume what you're hearing from your child and listen carefully before you decide on the answer
- Desensitise a child to the word 'no' by using it in other contexts, such as Yes/No games, when they hear the word without jumping at the sound
- Distract them before you get to the point where you need to say 'no'
- Replace where appropriate; if a child is twiddling your favourite

FURTHER READING

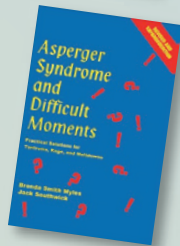
It Can Get Better...Dealing with Common Behaviour Problems in Young Children with Autism: A Guide for Parents and Carers

By Paul Dickinson and Liz Hannah
Published by the National Autistic Society.
ISBN 9781899280032
Available for £5.00 (bargain!) at www.autism.org.uk/products/core-nas-publications/it-can-get-better.aspx
NAS code 284.



Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage, and Meltdowns - Revised and Expanded Edition

By Brenda Smith Myles and Jack Southwick
Published by AAPC Publishing
ISBN 9781931282703
Available from Amazon for £14.95
www.amazon.co.uk/Asperger-Syndrome-Difficult-Moments-Practical/dp/0967251435



Functional Behavior Assessment for People with Autism: Making Sense of Seemingly Senseless Behavior

By Beth A. Glasberg
Published by Woodbine House Inc., U.S.
ISBN 9781890627584
Available from Amazon for £14.44
www.amazon.co.uk/Functional-Behavior-Assessment-People-Autism/dp/1890627585



The Red Beast: Controlling Anger in Children with Asperger's Syndrome [Hardcover]

By K.I. Al-Ghani
Published by Jessica Kingsley
ISBN 9781843109433
Available from Amazon for £11.69
www.amazon.co.uk/Red-Beast-Controlling-Children-Aspergers/dp/1843109433



The 4Rs: Regulated, Rumbling, Rage and Recovery



By Brenda Smith Myles, PhD

Brenda Smith Myles is an international speaker and consultant for the Ohio Center for Autism and Low Incidence and the recipient of the Autism Society of America's Outstanding Professional Award, the Princeton Fellowship Award and the Council for Exceptional Children, Division on Developmental Disabilities, Burton Blatt Humanitarian Award. She has written more than 150 articles and books on autism spectrum disorders.

Unfortunately, many children with autism fall victim to the 'volcano' and experience meltdowns over events that many would consider unimportant. Is the volcano on purpose? Generally not. We know that many individuals with autism have challenges in (a) recognizing emotions in themselves, (b) matching an emotion to an event and (c) calming themselves when they are upset. If they can perform these three steps, they are considered to be well regulated.

Generally, children with autism go through a four-stage cycle: (a) regulated, (b) rumbling, (c) rage and (d) recovery.

Regulated

During this stage, the child learns to react to the environment by (a) anticipating upcoming events, (b) adjusting to unexpected activities, (c) understanding how she is feeling, (d) matching emotions to events and (e) using supports and modifications (this may include leaving a setting - not as a punishment!).

Being well regulated allows individuals with autism to participate freely in life, making and keeping friends, shopping, holding a job and joining clubs. Learning to be well regulated is a significant challenge for children on the spectrum, but is one of the most important skills they can learn.

Rumbling

The rumbling stage is the initial stage of dysregulation. During this stage, people with ASC exhibit behavioural changes that typically appear minor and not directly related to what will occur during the rage cycle. Easy to overlook, especially in environments with many other students, these behaviours may include chewing on cuffs of a shirt, excessive blinking,

drumming fingers, nail biting, or tensing muscles. Each child has his or her own set of rumbling behaviours and the length of them vary. As these behaviours appear insignificant and are difficult to detect, it is sometimes easy to forget that they often indicate an impending crisis.

Rage

If behaviour is not diffused, the person may move on to the rage stage of the regulation cycle. At this point, the individual acts impulsively, emotionally - even explosively. These behaviours may be externalized (screaming, biting, destroying property) or internalized (withdrawal). Once the rage stage begins, it most often must run its course.

Recovery

When the rage behaviours subside, the individual moves to the recovery stage. Following a meltdown, your child might experience a behavioural 'slump'. He or she may become sullen, withdrawn or physically exhausted. Some feel bad about having exhibited rage. Others don't recall what occurred.

Summary

The rumbling, rage and recovery stages are the only way many children with autism know of expressing a host of emotions for which they see no other solution. Most want to learn methods to manage their behaviour.

The best intervention for dysregulation is prevention. Prevention is most effective when it includes instruction in strategies for problem solving, cause and effect, and understanding the environment, coupled with techniques that help self-understanding and methods of self-calming.

SARAH from Stockport, Cheshire, decided to home educate her children because she wanted them to learn at their own pace. "I wanted them to follow their interests rather than being forced to follow the National Curriculum and constantly having their ability measured against others, which we found had a negative effect on both learning and mental health."



WINNERS:
Team 'Home's Cool' won first prize in the Lego™ robotics competition at the recent Ace Robotics Extreme STEM event in Cheltenham. Sarah's children - ages 10, 8, 12 and 13, had to make remote control robots which then performed a series of challenges.



INSPIRED:
Raiden, 6, with his handmade puppet inspired by a recent visit to the theatre.

DAWN, based in Cheshire, says that she started to home educate after being 'badly let down by school'. Her children, she tells AuKids, were 'traumatised by their time there'.



LAURA G, based in Cheshire, says that home education wasn't her first choice "but we had no option. Our son was not progressing in the school system and he started to get more frustrated after school. His school wasn't giving him support and care - teachers were not able to teach him."



As the numbers of pupils with SEN in the UK is on the rise, many parents of children with autism have found that the standard education system is not adapting fast enough to meet the needs of their youngsters. We asked a group of those who've taken the brave step of home educating their children to tell us how they were finding the experience.

Was it an easy process to get started?

Sarah If your child has never been to school, you merely start to home educate as the child turns compulsory school age, the term after their fifth birthday. If the child is in a mainstream school, you simply write a de-registration letter to the head which takes immediate effect. If your child is in a special school, you have to contact the Local Education Authority.

Laura G To get him out of the school system, yes it was very easy. The school didn't put up much of a fight. However, getting my son right took a while. We had to deal with what had happened. He was bullied during his time in school, but only felt safe to tell me when he realised he wasn't going back. I had to work on his confidence and also find out what he could do and what he couldn't.

Laura P The biggest barrier I found was my own attitude. When you have been educated at school, and so has everyone you know, allowing yourself to open up to new possibilities is really difficult.

My daughter was quite damaged from her school experience, so I would say it probably took us a good six months to a year to properly find our way. The benefits, the freedom, started instantly though. Being able to visit places without crowds and queues is just amazing, it opens up the world to people with autism.

Victoria I did about three years' research off and on, I kept a book of useful websites, resources, materials, Facebook groups, podcasts... I got hooked on learning about learning! So, we didn't start overnight; it has been a slow learning curve and a slower decision!

What was your biggest learning point?

Sarah To relax and trust that learning happens constantly and naturally, so opportunities don't need to be manufactured. You don't need to buy every resource and book that you see!

Dawn Don't try to over schedule! Leave yourself some wriggle room and plenty of time at home. If you

are lucky enough to have a big local home education community, you will find so much to do, but there's no rush.

Laura G Realising that my son can't do what the school said he could do, taking his education back to basics and then trying to find the right way for him to understand it.

Laura P My biggest learning point was to trust, to back off and allow learning to happen naturally. It took me years of repeatedly seeing the difference when I stopped trying to lead the learning, to realise how wonderful it was to watch my children flourish themselves with the tiniest facilitation from me.

Victoria I think I have been surprised to learn that there are so many home-schooling methods/philosophies/cultures, which all have different results. As a former teacher, I think my youngest son, who learns in a very different way to most kids I've ever taught, has been the biggest challenge with learning. He needs to move a *lot* and I have to get creative with how to 'teach' him, almost so he doesn't notice!

What's best about home education?

Sarah Children learn at their own pace; you can provide a differentiated curriculum tailored especially for them. Being able to follow the child's interests and embrace their 'obsessions' is such a luxury; it enables quality learning, provides valuable life experiences and is an opportunity to grow in confidence!

Laura G Our autistic son when in school thought he was worthless and would blame himself because he couldn't do things. However, because I'm used to things he likes, like Lego™ or electricity, his outlook on himself has changed because he can do it. He is so much more confident.

Laura P The absolute best thing about home educating autistic children is the number of autistic children in the home ed community. The chance for my children to not be the 'different' ones, to just be part of the group and have a group of friends who understand - that is worth its weight in gold.

Emily We get to live relaxing

LEARNING ON THE SPOT:

“Learning Spanish the best way possible by listening to native speakers in Alicante, Spain. The chance to visit is open to us because we can go in term time – it’s cheaper and more importantly, because of their autism, it’s quieter!”

Laura P, based in Derbyshire, didn’t know her two girls were autistic when she decided to home educate. “I just knew that school was not a place where my eldest was happy or thriving, and most of all not an environment where she was able to learn”.



EMILY, based in Oxfordshire, says that home education was always their back up if mainstream school didn’t work out. “Even with an EHCP and 1:1 funding throughout most of the day, we could see everyone struggling and decided the best thing to do was to take control and do it ourselves!”

HISS-TORY LESSON: It’s all smiles when Timmy is learning with Severus his pet snake



CLAIRE, from the Wirral, has a ten year-old: “We tried schooling the traditional way, a mainstream school with a full EHCP and full time TA, but he was (in school’s words) “too autistic, too sensory.” After a number of other placements failed, she decided that Home Education was the only way.

VICTORIA lives in France but is moving to the UK. Her nine year-old son has autism and her six year-old has ADHD. “They both have fairly particular needs which I feel mainstream education cannot meet given the time frame we have and the importance of the job at hand,

DAB HANDS: Forest is 6, almost 7 and Brychan is 9



namely my kids’ education!”

lives, rather than wondering when the next meltdown will happen. We can see the learning happening in front of us, rather than coming out of school daily to disheartening reports.

Claire The way your understanding of your child changes, the chance to really learn with them and from them and, if your child had negative experiences, to see their improvements by what you are doing.

Victoria The time to pursue interest-led learning. ‘Mummy, where did phones come from?’ ‘Mummy, why is the sky blue?’ ‘Mummy, how do planes stay in the sky?’ Your child can direct you and you can use all the wonderful resources out there to answer these burning questions, because you have time!

There must be drawbacks...

Sarah There is no financial support for home education (some people may have an Education, Health and Care Plan - with a Personal Budget) so you will be responsible for funding resources, experiences and exams should they wish to sit GCSEs. Some people have to give up work to home educate, but some manage to find appropriate childcare such as forest schools and childminders to enable them to continue working.

Dawn Money! Unfortunately, we end up using all the Disability Living Allowance for home ed. which doesn’t leave it for anything else. We’re lucky to have the DLA though!

Laura G Everything is designed for children being in school, so when you say you’re home educating, people tend to react differently. They think you’re doing it for your yourself and that’s not the case.

Laura P The drawback of home education is the lack of funding and support, and the threat of interference of local authority officers who do not understand the needs of the children and the home education process.

Emily I really think it is what you make it. You could say a drawback would be less time for yourself with less breaks, but equally there is less worry about what is happening at school and more time with your lovely child, getting to know them on a deep level.

If someone else was thinking of doing the same, what advice would you give?

Sarah Make contact with local home educators - Facebook is a great place to find local groups. Most areas have an active home ed. community with opportunities to join activities or just hang out together and find support and friendship.

Dawn You will see your child shine and get the pleasure of watching them grow. If you contact your local home education group, I’m sure you will find many other autistic children.

Laura G It is hard work, there is no question about that. However, it’s so rewarding. I thought I

wasn’t educated enough to do it. My son, however, proved me wrong, he remembered things and he progressed. Don’t think that you can’t do it and that you’re not educated enough, because nobody knows your child more than you. The school system tries to fit your child around it. With home schooling you can fit the education around your child.

Laura P Go for it, it’s wonderful, we have been home educating for seven years now and we are so, so grateful that we get to live this life!

Emily Be flexible, open to suggestions and brave! Home educating isn’t everyone’s cup of tea and you may find negativity about it from others, but you know what is best so defend your right to provide the best education

for your child the same way you defend them in everything else!

Claire It’s been hard, because it becomes your whole world. But mostly, it’s been amazing. I have learnt so much about my son, about the world and about myself. Our son is once again happy and contented, and that makes all the hard stuff worth it.

Victoria Well, a great piece of advice I heard recently on a podcast was, make sure you have a pre-prepared answer to the ‘Why are you home-schooling?’ question. I say: ‘For the time and freedom!’. My second bit of advice is ‘Never say never!’ If it’s not working, try something else - there’s not just one home-schooling approach.

RECOMMENDED SITES

- The site www.notfineinschool.org.uk was formed by parents and offers great support if your child is struggling.
- The National Autistic Society on home educating your child: www.autism.org.uk/about/in-education/choosing-school/home-education.aspx
- Home education: www.ambitiousaboutautism.org.uk/understanding-autism/education/home-education
- Home education for autistic children: first choice or last resort?: network.autism.org.uk/knowledge/insight-opinion/home-education-autistic-children-first-choice-or-last-resort
- For Government information on home education, go to www.gov.uk/home-education
- EdYourself has details of practice and policy on home education: edyourself.org
- You can follow Sarah’s Facebook page on home educating her children here: www.facebook.com/electivehomeeducation

With thanks to Alex Seymour, The National Autistic Society’s Information Officer at the Autism Knowledge and Expertise Department ake.enquiries@nas.org.uk



'Smile like You Mean It'

How Should We Teach Social Skills?

By Debby Elley, mum to 16 year-old twin sons with autism

'Uhh! UH!!' Bobby, at the age of four, was reaching up with his eyes firmly on a small packet of raisins in my hand. Although he had no clear words, it wasn't rocket science to decipher this.

Give me the raisins. Or I am going to throw one massive wobbler.

And I would have done, except for I was accompanied by Bobby's first Speech and Language Therapist.

She had told me that in Bobby's world, there were only two things that counted. Him and the thing that he wanted. His autism meant that I didn't feature at all in this sort of scenario.

"We have to teach him that there is a triangle – him, the raisins and you. In order to get the raisins, he has to ask you."

People aren't just objects. People GET YOU STUFF. But only if you communicate with them - they can't read your mind.

Here endeth Lesson One if you're autistic.

So, I held back on the raisins until Bobby glanced at me. When he finally did, I said 'I want raisins! Good!' and gave them to him.

Since eye contact is genuinely painful for some people with autism, simply looking in my

direction to acknowledge me was all that it took to reframe Bobby's social programming. A week later and he had learnt very quickly that he had to look at me and not just at the raisins.

As Bobby grew older, he did seem to be particularly accurate when observing faces and I wondered later whether the simple raisin exercise had a profound knock-on effect on his ability to read signals from other people.

.....
"I have had to share with my son the strange, perplexing truth that unless you smile in greeting, you're generally assumed to be unhappy."
.....

If your sole focus is objects, it isn't very surprising that your ability to read faces won't be great.

That said, it would be a mistake to think that autistic people don't pick up any emotional signals from others. Plenty of people have learnt to compensate for the confusion that facial expressions can cause by having added sensitivity to body language and volume and tone of voice.

Given that social skills don't come naturally for people on the

spectrum, and take effort and energy, I've been faced with a dilemma.

How much should I teach my kids social skills?

In our modern culture, social skills seem to count for success in a manner that is frankly out of all proportion to their usefulness. Although I want my children to be able to relate to others when it benefits them, part of me also wants to tell everyone else to take a hike if they don't like it.

However, much as I'd love my kids to live in a place where they're understood, I'm not convinced this is going to happen any time soon. A degree of action is necessary. Teaching social skills might save them from harm and even from getting arrested.

When considering how to approach this, I'm often mindful that the 'fake it till you make it' school of socialising, often practised expertly by girls with autism, puts a tremendous strain on a person. Not only that, but it causes others to demand more of them than they may be capable of giving.

You look normal. You're acting normal. So what's the problem?

The trick, I reckon, is to firstly arm them with information and – if they can do it – let them adjust their social behaviour in a way that they're comfortable with. I'm quite a sociable person and – critically – a woman; if I asked Bobby to 'model' himself on my social behaviour, it wouldn't sit right with him. Mothers are often social teachers, so do consider this when approaching situations with a boy. To state the obvious, they're a bloke!

At home, we start with the 'WHY?' and work backwards.

Let's take greeting with a smile as an example. I explain that certain 'niceties' make others feel comfortable and welcome. Then I explain what happens if you abide by the unwritten 'rule' and what people imagine when you are unintentionally breaking it.

If Bobby then decides not to follow the smiley greeting this is fine, but at least he understands the effects of not doing so (although this may need to be

explained more than once).

If you explain the implications, (presuming that the child you are working with can understand them - Bobby's twin Alec wouldn't) then they can weigh up whether their effort is worth it.

The key to sustaining self-esteem and to teach social skills in depth rather than superficially - is to raise awareness of the meaning of social 'rules' rather than telling a child to copy you or anyone else, and certainly rather than reproaching them for behaviour that feels natural to them.

The truth is, our social practices aren't even logical. If you tell an autistic person to smile at someone when they're happy, you're ignoring the simple fact that we also smile at people when we're not.

It's easier to explain what we mean by a smile and what people read from our faces when we aren't smiling. I have had to share with my son the strange, perplexing truth that unless you smile in greeting, you're generally assumed to be unhappy.

Sounds like hard work for a parent? You bet. It involves analysing what you do naturally and it isn't easy. You may not be that great at it. But you'll be more aware than they are.

In life, it's a fact that more doors open if you are positive. A positive state of mind tends to be reflected in a smile.

Think Tigger and Eeyore.

So, I arm him with the information and let him decide how hard he wants to work. At the same time, I'm reinforcing that this is just stuff non-autistics do and that he's fine just as he is, more honest in fact... it's just that unfortunately the rest of the world is a bit bonkers.

No one said it was easy being an autism parent.



Debby Elley is the co-founder and co-editor of AuKids magazine. Her book **15 Things They Forgot To Tell You About Autism** is available from www.jkp.com



The Hidden Power of the Special Interest

Author and speaker Helen Clarke is the founder of **Helen Clarke Autism**, an autism training and consultancy service, which she established after 20 years' experience working with and teaching autistic children. As an autistic woman, Helen is keen to share her own life journey and what she has learnt from both academic studies and her extensive teaching career. She has four children - one of whom is an autistic daughter - and is also passionate about ensuring that autistic girls can achieve their full potential and that well-being and mental health should be a priority in schools.



Back in the Seventies when I first started at school, I knew immediately that I wasn't like the other children in the class. My earliest memories were of feeling frightened and overwhelmed and I'd often wish I could be back at home where I felt calm and safe. No-one ever mentioned the word 'autism' in those days because it was a little-known condition. It took a further two decades to learn that I was autistic.

As time passed, I became more familiar with routines that made life more predictable, but school overloaded me mentally, drained me physically and caused me anxiety. I therefore learnt to seek out activities that allowed me to be myself, helped me to feel calm and made me feel happy. Often this involved being creative, exploring things I found interesting visually and drawing.

I remember for example being captivated by colourful prisms in a quiet corner of the classroom, being transfixed by the delights of the 'nature table' and I could quite literally lose myself for hours creating highly decorative drawings - it was all about the detail for

me because I was a perfectionist. Sometimes I would be so highly focused and engrossed in my work that I would fail to hear people talking to me. I was lost in my own thoughts, in a world of my own, but was able to feel calm in that moment.

.....

"It's at times of high anxiety that I'm more likely to focus on my intense interests to calm myself down."

.....

Being able to pursue an interest in extreme depth or for long periods of time can be referred to as an 'intense interest.' Sometimes people use the term 'special interest,' whereas others simply prefer the word 'hobby'. Intense interests can sometimes seem unusual to other people but having different preferences and abilities is what makes each person unique. Having one very specific interest can feel safe and predictable (as life isn't) and the extent to which autistic people are able to step out of their usual routines or comfort zones will vary greatly as change can cause stress.

Although focusing on one specific subject can be viewed as repetitive behaviour, often one interest can develop into another. So not only did I enjoy drawing as a child, I then developed a passion for reading about artists and enjoyed trips out to the local art gallery which broadened my horizons.

Intense interests enable autistic people to become highly skilled in

a specific area and this can lead to meaningful and worthwhile opportunities, further study or careers.

With a keen interest in art, I studied Illustration and later became an art teacher, working with autistic children. I continue to enjoy being creative and consider it to be one of the strengths of being on the autism spectrum. Everyone has a skill or talent.

Over the past two decades, I've encouraged autistic children to discover their own strengths (which often stem from their interests) because this can help build confidence and self-esteem as well as a strong, positive identity, all important for well-being.

Intense interests can have a positive impact on mental health and research tells us that compared with non-autistic people, autistic people are much more likely to experience anxiety. It's at times of high anxiety that I'm more likely to focus on my intense interests to calm myself down (self-regulate) enabling me to recharge the batteries.

Overload can be caused by a range of factors such as having too much language to process, the sensory environment or having to navigate social situations. Being over stimulated is like having a busy brain that doesn't want to switch off, although the body feels tired. This can affect sleep.

As a busy working mum of four children (two of whom are autistic) I don't have much spare time for drawing now, so have to think of alternative ways to wind down. Swimming or walking fits in well with family life.

It's important that autistic children are given time to pursue their own interests both at school and at home and it's helpful for them to know *when* this is going to happen and for *how long*. Visual timetables and schedules can be useful.

Some autistic children struggle to transition between activities and find it difficult when told to stop doing something they are enjoying. A visual countdown or sand timer can help some children prepare for change, gradually.

If an interest is having a detrimental impact on life, it then becomes an obsession, but we can support that person by seeing the 'bigger picture' and considering what we can do to help them to feel calm.

- How can we adapt the physical or sensory environment?
- Does the child need more routine, structure or predictability?
- Does the child need more time alone with less language to process?

As an adult I am fortunate to use my intense interests in support of autistic children. I deliver autism training to schools and organisations and work directly with autistic girls through my Spectacular Girls - Well-being Workshops. I'm also currently writing and illustrating books to help people understand the needs of autistic children, which is a very rewarding job.

To find out more about Helen, or to approach her for a speaking engagement, go to www.helenclarkeautism.com





The Last Word

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

Feel the Fear and Do It Anyway

AS we prepared to drive to Salford Quays to see the free 'Lightwaves' installations, I felt a familiar sense of trepidation. Lovely light shows in the dark aren't to be missed. But then, there's that 'anything could happen' feeling familiar to all parents in my position.

For everyone else, there's a few things to consider. How are we going to get there? Where are we going to park? But as autism parents, we have an extra layer of anxiety. If our logistics fail, it won't be good news.

If we turn around to find another car park, for instance, Alec will express his confusion by launching at his twin. One of my eyes will be looking for a car parking spot, the other eye will be assessing the drama unfolding in the rearview mirror.



LIGHT UP YOUR LIFE: Part of going anywhere is assessing how much space you get to yourself. In our case, the Quays have ample room for a quiet wander away from crowds.

Then when we get there, some event warden will no doubt order 'only ten on at a time' at a light-up exhibit and I will bite my lip, hold Alec's hand and scrunch up my toes, doing the old 'Very patient! Good waiting! Nearly time!' sort of thing whilst hoping that I won't be put in a headlock any time soon and wondering whether it would very much noticed if I trampled over a toddler or two to give him a turn.

It's enough to stop anyone doing anything new. But then, this Lightwaves event, it actually went well! Preparation paid off, the less busy (expensive) car park researched

beforehand was a triumph and the whole thing was a success. What was I worried about?

The answer is simple. Usually, when we plan in advance, taking into account all the factors that could cause a problem, things go pretty well.

The problem is, the times when things *don't* go so well are so deeply etched in my memory that they greet my nervous system with a flashing siren if I'm planning on repeating anything similar.

As that fabulous author Susan Jeffers once said, I have to 'feel the fear and do it anyway'.

Of course, what we're experiencing is exactly the same as what autistic children do, only once removed. Because they have fear and anxiety going somewhere new, we do too, on their behalf. But providing we've adequately prepared, that should be no reason to stop us from expanding their experiences. Every new one adds to the repertoire of things that they are prepared for.

In preparation for going somewhere new, these are the things that I've found help the most:

- Find out what you can; ask other people who've been there to report back.
- Do your own preparation and show your child photographs (or You Tube footage) beforehand.
- Take someone really helpful with you (rather than someone you like, but who is less than helpful in a crisis or who has kids of their own to deal with).
- Choose the place and the time carefully.
- Pack food and small toys as back up for waiting times.
- Be prepared to cancel or amend your plans if your child is showing signs of agitation.
- Then...give yourself a pat on the back. It takes bravery to face the unknown when you're accompanying someone on the spectrum.

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

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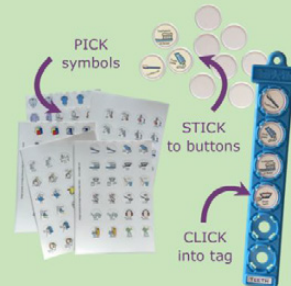
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