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Issue 17
Autumn 2012
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Positive Parenting for Children with Autism Spectrum Conditions



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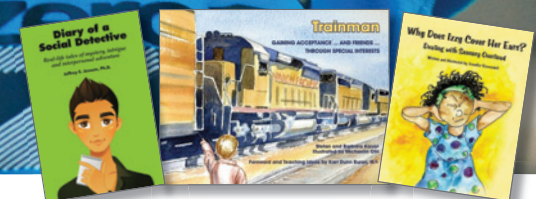


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Letter from the Editors

Debbly Tori



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Together we work across the autism spectrum from birth to adulthood. We provide independent diagnostic and specialist assessment, speech and occupational therapy assessment and delivery. We also provide consultancy, training and ASC sleep clinics for parents and professionals.

Together Trust ASC specialist services include:

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www.togethertrust.org.uk/services/autism
enquiries@togethertrust.org.uk

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Welcome to our AUTUMN ISSUE!

Firstly, many thanks to those of you who voted for us in the National Diversity Awards. Sadly, among the many good causes, we didn't manage to get short-listed. Debbly was still petulantly stomping around the office about it when Tori suggested that we ran our own AuKids awards. What a great idea! Why didn't we think of that? Oh, we did...watch out for details in the January issue of how you can vote for your favourite autism toys, books and apps.

The beauty of these awards is that whilst people vote on Facebook, other readers will get a wealth of ideas on what's great out there to choose from. Winners will be published in our 5th birthday issue in summer 2013.

A quick thanks to AAPC Publishing in the USA for not only going to the trouble of shipping us some award-winning books to review and as prizes, but also supplying a top advisor for this issue from across the pond - Brenda Myles Smith. We hope you enjoy her expert contributions.

Finally, a big mention to Carol Newbury Smith and her husband Bernard. Their grandson Joe has autism. The couple sent us a donation for £175, explaining that Bernard had won the money and decided to send it to AuKids.

Carol explained: 'Bernard's hobby is drag racing and he won the

prize money at a meeting at Santa Pod Raceway where they had some night racing (night racing and prize money doesn't happen too often). I have really enjoyed reading your magazine, I have learned a lot, and he asked me to donate the money to you.

'If it hadn't been that there was some oil on the track, he would have made a better time and would have got more money - but hey ho, better than nothing!'



SPEED DEMON: Bernard with his car

Can't tell you how touched we are when readers send donations to us. We love working on AuKids and it especially helps to know that what we're doing makes such a difference to you.

See you next year!

Tori & Debbly

Happy to support
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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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PRINTING:
R and P Printers, Dukinfield

GRAPHIC DESIGN:
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Front cover photo of child using app - courtesy Mayer-Johnson.

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A P P S

Reviews



Cause and Effect Sensory Light Box

By Cognable

iPhone / iPad App £1.49

Cause and Effect Sensory Light Box by Cognable was created as an iPad app for a group of teenagers with complex needs including visual impairment, autism and developmental disabilities. This latest version (1.1) has improvements to the speed of graphics.

So, gone are the days when I'd pack half the house in an effort to entertain Alec when we went on a visit. Gone are the days of bursting a zipper by trying to squeeze a giant Leapfrog game into a bag alongside a change of clothing and all his other clobber.



All you need now is a Smartphone and a couple of quid. This Sensory Light Box is wildly entertaining for any child (or adult, ahem), but for a sensory seeker like Alec who has complex needs, it's a must. He can delight himself with snowflakes accompanied by deliciously satisfying bell sounds, falling leaves with fizz, colourful explosions to the sound of smashing glass (satisfying if you're in a bad mood) and my particular favourite, mini hearts drifting to a hint of jazz. There's no boredom here - 21 effects will keep anyone happy for a while.

My only criticism is that to flit between the effects, you have to locate an exit button that is tiny on a Smartphone, but with Alec this hasn't been a problem - his motivation has been high enough to help him tolerate any fiddly bits and so it's good for motor skills, too.

It's calming, distracting and entertaining - any place, any time. We're so lucky to be the generation to have this at our fingertips.

Debby Elley



BOOK

Life with Trainman - Gaining Acceptance... and Friends... Through Special Interests

By Stefan and Barbara Kavan

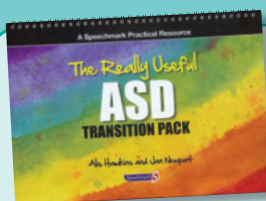
Published by AAPC • £14.50 • ISBN 9781934575703

Life with Trainman is an inspirational, emotional and easy to read book which will appeal to children, teachers and parents. It is written by Stefan Kavan, an adult with autism, and his mother, Barbara Kavan. The story is written in a format designed for children and there are some lovely, colourful illustrations by Michaelin Otis who has a son with autism. Trainman is based around the experiences of Stefan as a student in an elementary school. Stefan describes the difficulties he had in developing friendships due to his intense interests in trains, maps and numbers which made it difficult

for his classmates to understand him or get to know him. The book highlights how it's okay to be different and that special interests can be turned around to become a strength. Stefan's story shows that with the right support and acceptance from teachers and peers, individuals with autism can have positive social and academic outcomes. This is really useful as a teaching tool and there are some good ideas and resources at the end of the book which can be photocopied.

Tim Tuff, adult with autism, and his support worker Francesca Sephton.

We have two copies of Life with Trainman to give away to the first two readers to write to us by November 30th. Write to AuKids at auidsmag@gmail.com with 'Trainman' in the subject header.



BOOK

The Really Useful ASD Transition Pack

By Alis Hawkins and Jan Newport

Published by Speechmark • £45.00 • ISBN 9780863888397

The Really Useful ASD Transition Pack will help anyone whose child is moving from mainstream primary school to secondary school. It comes with a DVD, so you can fill in any of the forms featured in the book on your PC. If you and your school work your way through it together, you'll end up with a really comprehensive and defined record of how each part of your child's day is currently approached.

The pack has a blank Classroom Record followed by a filled in example showing specific

difficulties that a child has experienced with school work and what was done both in the short and long term to manage it.

Most of the pack is taken up by the Provision Record in which you can give a detailed description of every type of school situation and what provision is necessary. There's a lengthy section giving examples of the provision records for five different children. Not only does this help you with filling in the section, it also gives you plenty of ideas for great practise.

Finally, there are some great practical solutions to photocopy, including a 'tension thermometer' and an 'understanding measure', plus useful guidance on visual timetables for older kids.

All in all, a handy resource for any primary school to have at their disposal and if your school has a number of children with autism, the pack becomes even better value.

Debby Elley



BOOK

Why Does Izzy Cover Her Ears?

Written and illustrated by Jennifer Veenendall

Published by AAPC • £15.95
ISBN 9781934575468

Despite the odd Americanism, which we suggest you dub over when reading aloud using the British version, this book is a great little guide to sensory overload. The author is a school-based occupational therapist from Wisconsin and has used her considerable writing and watercolour talents to bring about this colourful tale of a little girl whose problems at school stem from a

sensory processing disorder. It means that she gets over-whelmed by sounds and can over-react to touch. The story's simple language helps to explain to children who have sensory processing problems - and their friends - what causes difficulties, why, and gives some easy techniques for reducing overload and inducing calm.

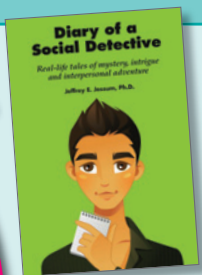
There's a 'grown-up' explanation of sensory processing disorders in the back of the book, as well as a really helpful resource list for teachers and parents, a list of useful websites (US ones) and recommended children's books. A great read for parents and teachers alike.

Debby Elley

We have three copies of Why Does Izzy Cover Her Ears? to give away to the first readers to write to us by November 30th. Write to AuKids at auidsmag@gmail.com with 'Izzy' in the subject header.

Win a Copy!

We have copies of The Diary of a Social Detective to give away to three lucky readers. All you have to do is find the magnifying glass hidden in AuKids. Send your answer to auidsmag@gmail.com or write to AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE. Clearly mark your entry 'detective'. The first correct answers will win a copy. Send them to us by December 10th 2012.



BOOK

Diary of a Social Detective

By Jeffrey E. Jessum

Published by AAPC • £16.50
ISBN 9781934575710

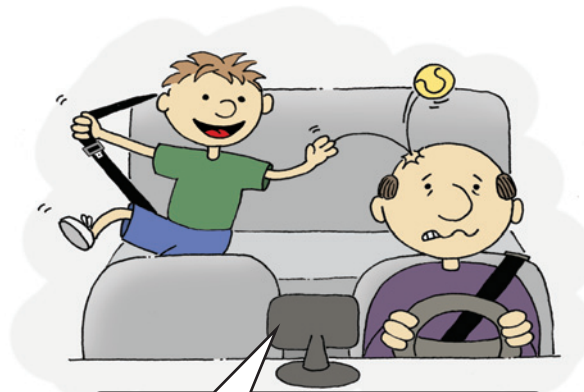
Johnny has difficulty fitting in and making friends. Although he is bright, he finds the social world a complete mystery. Outside of school he loves playing detective and solving mysteries and puzzles. So he decides to use these skills and focus on solving social puzzles. As he collects facts, makes sense of them and creates social remedies, he begins to understand the social world better. With his peers, he goes from 'Johnny Strange' to 'Johnny Smooth'. Soon, they want his help in solving their own social mysteries. This book contains short stories about the social difficulties Johnny's friends encounter and how he helps them to understand why things are going wrong. Each story contains a social difficulty that

young people with high-functioning autism or Asperger's may experience and this book provides a great context in which to discuss and share the issues that arise. Great for our children who struggle to understand why the social world is so complex!

The Diary of a Social Detective has recently won the USA's 8th Annual Teacher's Choice Award for the Family and is the Moonbeam Children's Choice Award Winner. Its author has spent 15 years working with children and families in hospitals, mental health facilities, schools, private practice and the community, with a primary emphasis on social skills training and education.

Tori Houghton

“Driving with my autistic child can be a challenge. He can't sit still, finds his way out of his seatbelt and is disruptive to the point of making it dangerous for the driver. Can you help?”



Turn around when possible, then go back home and sit in a dark room with a stiff drink



Chris Barson
RNMH, GWCMD Dip

Chris is the founder of training company Positive About Autism
www.positiveaboutautism.co.uk

Prior to that, he was External Training Manager with the National Autistic Society and still delivers training for the charity. He is a contributing author to *The Autism Spectrum in the 21st Century: Exploring Psychology, Biology and Practice*
Jessica Kingsley Press 2010

Firstly let's get the tricky bit out of the way. The following ideas are illustrative - they don't constitute advice. Only you know your child well enough to determine the best way to keep them safe.

If it's not safe to drive, don't. Stop. It might be an idea to have an 'in case of emergency' number (or numbers) ready to hand. Agree with a couple of close friends or family members how they can help you if you get stuck some place and can't drive. Avoid roads like motorways where you can't stop - at least until things are more under control.

Devices like a Buckle Boss are about preventing the young person releasing the seatbelt. And some do a pretty good job of that task. Of course this is not a long-term strategy because it doesn't deal with the cause of your child's distress.

Children with autism are pretty 'sensory' beings. It's hard to think of an experience that interacts with the visual, hearing, proprioceptive, touch, and smell systems like driving does. Noise cancelling earphones or a pair of ear defenders might be enough to take the edge off.

A car journey is always headed somewhere and sometimes it's returning from that somewhere. Use pictures, video, symbols, object reminders that will help the young person know what's going on. It's strange but unless you make it explicitly clear, young people with autism don't 'know' that they will return home. Make sure that you have the communication right.

What does your little person do to de-stress themselves? I'm talking about the flapping, twirling, spinning stuff! And the noise making, smelling, touching etc. Do they have access to this in the car? If it can't be done in a car then something that mimics the effect is essential. I have often wondered about making a video of the person doing some of the above and playing it to the person to see if it works (maybe on an iPad or in-car video system). You never know.

For more able kids, get them involved with the whole process of the car and its journey. Make them co-driver! That'll involve pre-drive checks, route planning and guidance, monitoring car systems...Weapons coordination (joke).

Last but not least there is the 'green, safe, healthy, alternative approach'. That is bus, tram, train, walking, running, cycling... Don't knock it till you've tried it!



Breanne Black
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There is a three-step approach in terms of suggested strategies to trial in response to this situation:

Preparation

- Allow the opportunity for calming and organising movement in combination with 'heavy work'* in order to regulate and organise the child's nervous system in preparation for the journey. So, you may wish to encourage them to help you load the car. Wearing a weighted backpack beforehand, (maybe with sensory toys inside) may help.
- Use Social Stories™ to emphasise the importance of safety within the car, such as wearing a seatbelt. See Issue 15 (downloadable online for subscribers) for how to write one.
- Use a visual schedule (you can draw it) to illustrate the sequence of the car journey, including using a seatbelt. This will help your child to know

* 'Heavy work' means exertion using push and pull forces - it is a method of calming often used in occupational therapy.

what's happening next, having a clear start and finish point.

During the journey

- Use a seatbelt with a buckle guard (see further info) to prevent a child from deliberately unbuckling.
- For calming, use weighted toys. You can also use lap pads, weighted vests or pressure garments like hug shirts.
- Create a portable sensory box filled with favourite books, fidget toys, chewy items and crunchy snacks in order to provide calming and organising sensory input (the jaw provides a lot of sensory feedback to the nervous system) and occupy fingers and hands. The use of ear defenders can be good for sensitive ears.
- Other distractions such as portable DVDs, CDs and computer games are good. Your child may also enjoy tracking the route, identifying landmarks on a familiar route or searching for specific items if on an unfamiliar journey (e.g. how many blue cars, Christmas trees, etc. can you spot?).
- Use additional harnesses if necessary. These need to be bought from recognised suppliers and fitted to meet safety regulations.
- Provide breaks for running around if the journey is lengthy, shown on the visual schedule.

End of Journey/Safe Arrival

- Use praise, even a reward chart, to reinforce good behaviour on a journey.

SOMETHING TO CHEW OVER



Chewigem's new Dog Tag range

Chewigem offers a range of discreet jewellery that children can chew on! Born from a teething jewellery idea, many of the original designs were quite girly, but having listened to requests for more masculine designs, brand new looks are available in 'Dog Tags' and 'Chubes'! These are non toxic, washable and available at £12.50 from www.chewigem.co.uk

AuKids is offering 4 lucky readers the chance to win a Chewigem in a design of their choice. Just look on the website to find the answer to this question: **What is the name of the black Dog Tag?** Send your answer to aukidsmag@gmail.com or post to AuKids magazine, PO Box 259, Cheadle, Cheshire SK8 9BE before November 15 2012.



Brenda Smith Myles
Ph.D.

Brenda is an international speaker and consultant for the Ohio Center for Autism and Low Incidence. She is 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.

Keeping a child with autism seat-belted in a car can be a challenge. The keys to success include:

- (a) understanding why the child does not want to be seat-belted
- (b) making sure that the child understands that she must be seat-belted
- (c) distraction and
- (d) reinforcement.

These four topics are discussed briefly below, keeping in mind that wearing a seatbelt is not negotiable.

Many children with autism have sensory problems, and seat belts can be very uncomfortable for them. For these children, placing a soft sleeve over the seatbelt may make it easier to tolerate. Travel vests, safety harnesses, or seatbelt

adjusters can also help the child with sensory issues (www.ezonpro.com; www.perfectlysafe.com/travelvest.htm; www.mypreciouskid.com/seat-belt-adjuster.html).

For some, seatbelt difficulties are related to the concept of time and processing what adults say. A child with autism may think that he will be belted in for an extended period of time and may not understand that there is a specific destination. For such a child, consider placing a timer or watch in the car and providing a picture or written description of the destination.

Other recommendations include:

- Write a social narrative or draw a cartoon that explains that the child must remain seat-belted. Make sure that you indicate how you as the adult feels when the child is safe in the car and when he is not.
- Keep an item in your car that your child likes. This item is only accessible in the car. It could be a special book, toy, music, or handheld game.
- Reinforce the child for keeping their seatbelt buckled. Specific verbal reinforcement such as: "I like the way that you are keeping your seatbelt buckled," can be effective. Or, if the child needs something more tangible, provide a small reinforcer at the end of a successful trip. If the child needs a reminder that a reward is coming, they can be given a picture of the reinforcer along with the picture of a seatbelt.

Further Information

- Buy Bucklesafe™ for £9.95 from www.bucklesafe.co.uk
- Hug Shirts are available from www.sensorydirect.com
- Fidget boxes are available from www.thesensorytoywarehouse.com
- You can buy Edz Kidz Ear Defenders from www.amazon.co.uk, ranging in price from around £12-£15.
- A company called Crelling Harnesses manufacture a large range of belts and harnesses designed to provide Postural Support or restraint for disabled children and adults. Look up www.crelling.com, e-mail jennyf@crelling.com or call 01253 852298. Please mention AuKids when you contact any of these places.



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chewable jewellery
Great for stopping
chewing of unwanted
items & keeping children
calm.**



www.chewigem.co.uk



Time Specialist Support

Specialist support services for children and young people with Autistic Spectrum Conditions

Given the special requirements of autistic children it can be difficult to find someone who you feel comfortable with, who understands them and has the experience of working with them. This is where Time can introduce you to people who have already been reviewed and who have experience of and an interest in working with autistic children.

Time Specialist Support Workers are all over 21, CRB checked and have experience of working with children and young people with autism. They all complete an insight into autism training.

"This is the only service ever which has provided the exact support I have wanted for my son for years now!"



Tel: 07942815845 Email: tori@time-specialist-support.com
Web: www.time-specialist-support.com

**Do you have a question for Ask the Experts?
E-mail us at aukidsmag@gmail.com**



APPS-olutely Fabulous?

OVER the last few years, a massive rise in the use of learning tablets for kids with special needs has been well documented. The benefits to autistic children have also been highly publicized, and rightly so. Autistic kids are often highly visual learners, many of them comfortable with technology, so tablets play to their strengths. But before we get too swept away by this tide of technology, we need to learn how best to use it. Cheaper tablets are starting to come on the market, and if one is high on your Christmas list, have a look at AuKids' handy guide to using them effectively.

YES there are massive benefits to this smart new stuff, but we'd also like to urge a word or two of caution. Even experts who make use of technology when working with autistic children advise that the tablet is only a smart thing if you are, too.

SEN Assist director Adele Devine is someone who has made great use of technology in order to help autistic children. Adele and her husband Quentin develop award-winning educational computer games for children with autism. This year, the company is branching out into free apps. She welcomes tablet technology, but is careful to point out that for every coin, there's a flip side.

"Children with autism benefit from structure. If left to their own devices they might be on the computer all day and do nothing but click between YouTube videos or sound files. We've got to take control early on and structure their time so that they develop a healthy relationship with it."

In an article for her own website, Temple Grandin backs this view. "Young children with autism need reciprocal interaction with a good teacher. To be effective, the tablet's use must be facilitated by a teacher or parent who keeps the child on task and prevents the child from stimming (repetitive behaviour) by moving the icons."

Adele suggests having 'computer time' so that it becomes one of *many* daily activities as well as encouraging a range of different activities on the computer itself. She also advises against apps that 'speak' for a child before they're six.

As well as making sure that computer usage is appropriate, AuKids co-editor Tori Houghton says that parents should take a questioning stance when faced with such a mouth-watering array of interactive software.

"There's a danger in believing that all you need to do is give a child an iPad and this silent child will start interacting with the world. You still need to teach them to communicate. I think parents have got to really think about what a particular app is for. What's the purpose? The benefit is only as good as the suitability of the app itself for your child's particular needs."

Something else to watch out for is your child's understanding of what this is all about. Whilst parents are readily flexible about a learning tablet's variety of uses, an autistic child may be far less so: "If they think this is a games console, like a Nintendo DS, and they're only going to use the tablet to play games on, they may be reluctant to see it as a communication tool as well," says Tori.

If you think about it, the tablet is the ultimate abstract device – it can be pretty much anything you like – and abstract concepts are hard for autistic children to grasp.

Tori suggests a visual cue such as different colour tablet frames may be a great way to help the child understand the different ways of using a tablet in a more concrete way.

Any Old App?

Do we think apps are a good thing? You bet we do. But not just any old app. Tori explains: "You need to start by thinking - what do you want the app for? If the child is at the 'cause and effect' level, and you want them to understand that if they touch something, something else happens, there's loads of apps that are brilliant for that. If you want it to promote communication, then you have to select the right kind."

So here's our guide on what to look for, when and why.

What We Love About the Tablet

It's age appropriate! Hurray, any child, wherever they are on the spectrum, can look cool and learn at the same time.

It's a touch screen! Hurray, children who can't control a mouse get the ultimate buzz from being able to manipulate what's on the screen all by themselves.

It's mobile! Hurray, you can take it anywhere, any place. Hold on, isn't that an advert for something else...?

What They're Good For in General

Asking: Merely having an attractive interactive bit of kit is an opportunity for the child to request Smartphone or learning tablet time. Asking for help on the tablet is also great for speech therapy, too.

Behaviour support: Support your own behaviour strategies by using apps that help to calm a child down, or use Smartphone/tablet time as a reward or motivator.

Concentration: For fiddlers and twiddlers, educational games can be great for focus and distraction.

Sharing: Adele Devine says: "I had one child in my class who liked to video her journey to the taxi at the end of the school day and then show the child sitting next to her. This was such a positive end to the day for her and made a huge difference".

Waiting: Cause and effect games on a Smartphone can help kids to wait in queues.

Entertainment: Particularly for children who tend to find it hard to amuse themselves, games can be a great source of safe fun.

Fine motor skills: There's nothing like creating a virtual cupcake to get those little fingers dragging icons around a tiny screen – hugely motivating!

Trial and error: Apps may generate an enthusiasm for something that sparks an interest in its real life equivalent. This can be great for autistic kids who are reluctant to try something new.



Reader Natalie Barnes sent in this picture of her son Elliott, age four, using his iPad. Elliott has autism and learning disabilities.

The APP-roprate Option For Autism

If you want to go beyond the fun component of tablet technology, look for games that will enhance your child's development in one of these three main areas.

1 Communication

Choose apps that help a child to have control of their own communication and that give them the freedom to express themselves.

Support a child whose receptive language (what they understand) is still developing by playing an app together. Make sure the app is at their level of receptive and expressive communication.

Choose games that test language learning and the development of understanding of the separate components of language e.g. Spingo's Language Universe. Ideal ones can show evidence of progress, reward it and have different levels for when the child improves performance.

AuKids recommends:



Yes-No by Smarty Ears. We reviewed this last issue – it's the simplest idea, just a vocalised graphic depiction of 'yes' and 'no', but can be used in a multitude of situations where speech is either not present or stunted due to stress. Preposition Remix by the same people is great for those whose language is a bit more developed.



Spingo's Language Universe by Talking Wizard. Great fun whilst learning nouns, verbs, adjectives and prepositions. Fully adjustable to your child's level with built-in rewards.



Grid Player by Sensory Software International. This is a mini communication device. Hugely complex, it provides a voice with symbols in a range of categories and is free!



SmallTalk – oral motor exercises by Lingraphica. More a speech therapy tool, but good for encouraging copying.



The Grace App for Autism by Grace App Communication. Builds sequences from relevant images to form sentences. The app can be easily customized by using your own pictures and photos.



PCS™ range of Apps by Mayer-Johnson, (the name behind the Boardmaker symbols programme). A range of fun apps to develop language, understanding and articulation.

2 Imagination and Education

'Cause and effect' games can be good for pre-verbal learners.

Any game that requires designing a character or dreaming up a new world is good for the imagination.

AuKids recommends:



Pocket Pond by TriggerWave LLC. Tremendously calming. Add fish, dragonflies and lily pads. Feed the fish. Bring on a thunderstorm. Relax to the gorgeous splashing sounds when you touch the screen.



Lightbox by Cognable. Delightful cause and effect fun, reviewed on Page 3. Their Soundbox app is equally awesome.



Creative Genius On-the-Go! by Jr Imagination. Bit of brain exercise to encourage youngsters to think of ideas, with lots of 'what if?' questions. Ideal for developing imagination.



Fireworks Arcade by Big Duck Games LLC. Pocket firework fun.



Social Interaction

Apps that facilitate social interaction are best. The iPad app Stories About Me is designed for parents and teachers to create their own Social Stories™ using text, photos and voice recordings.

AuKids recommends:



Using My Words by Touch Autism.com. One of a range of Social Stories™ by the company to encourage kids to use language even when under stress.



Stories About Me by Limited Cue, LLC. Allows children to develop their own Social Stories™ and share them with parents, teachers and friends.



First Then Visual Schedule by Good Karma Applications, Inc. Helps support behaviour and social skills with a personalised visual board.



My Choice Board by Good Karma Applications, Inc. Presents a visual display of 'choices' for those with limited communication skills. Helps build independence and expressive skills.



Calm Counter by Touch Autism.com. A countdown and Social Story™.

Note, not all of our recommendations are available on every type of tablet.

Share your child's favourite apps with us and we'll revolve them on our home page at www.aukids.co.uk. Send your ideas to aukidsmag@gmail.com, telling us briefly why your child loves the app and how they react to it.

Mind The G-APP

Apps can never replace the learning that takes place by socially interacting with another person.

What they can do – and can do well – is to help facilitate that social interaction by making it easier for the autistic child to get their point across easily and quickly. When developing a child's communication, look for the apps that facilitate interaction with the outside world rather than encourage them to withdraw further into their own world.

For highly verbal children, this could mean supporting communication and developing the means of describing complex feelings. For less verbal children, an app can provide a voice for thoughts that may not otherwise reach you.

Don't Get Addicted to Tablets

And don't forget, although tablets are sexy, pen and paper can be an equally powerful device. The physical exchange of a PECS card is also something that is really meaningful for communication, and can't be replaced.

Tablets have their place, but they're just one piece of a far bigger picture. Use them wisely, and they could become a great part of your autism toolkit.



Further Information

Netbuddy

Check out Netbuddy's great advice guide for some more great examples of autism apps and tonnes of superb links to find out more: www.netbuddy.org.uk/info-packs/apps-ipad

For CD-ROM games produced by SEN Assist, look up www.senassist.com or check out their new blog at www.senassist.com/blog/

Watch out for their new **FREE** Red Riding Hood game app.



FURTHER READING

Apps for Autism by Lois Jean Brady, published by Future Horizons. ISBN 9781935274490. Paperback £24.50

This is an ever moving field and the book will obviously go out of date but if you want more specific ideas, you'll find plenty here.



Mayer-Johnson offers 30 day free trials of all its software – this includes all versions of Boardmaker, as well as the pre-made Boardmaker Activities. Try the Beginning Board Games and Quiz Shows series – both support turn taking and interaction whilst also facilitating conversation. All of the trials can be found here: www.mayer-johnson.co.uk/downloads/trials

Karen Sweeney sent us this picture of her daughter Phoebe, age three, she told us "She is amazing on it, we constantly add new puzzle apps and she completes them in seconds".



THE VIEW FROM MARS

Is it different for dads? We wanted to know how the dads among our readers felt about their role. Here's what they told us. Other dads who took part in our interviews are quoted in planets. Typical AuKids, really...



GARETH CHILD is married and has three children. The second, Benedict (Ned), seen here on the family's narrowboat, is 12 and has autism. Gareth runs the popular parent forum ASDFriendly (www.asdfriendly.org).

MARK TUBBS has been a serving member of HM Forces for 21 years and his nine year-old son Robert has Asperger's. He and his wife Sam also have an older daughter, Steph. Mark is pictured here with Steph and Robert.



SIMON JOHNSON has an autistic daughter, Mollie (pictured), who is nine. He's married to Claire, and they have another daughter, Daisy, who is six and does not have autism.

GAVIN ELLEY has eight year-old autistic twins, Bobby and Alec (Alec pictured). He is married to AuKids co-editor Debby Elley.



What do you see your role as?

Gareth: My wife and I have never been much for gender differences in parenting roles. My wife's disability meant that I did the night feeds for all our babies anyway, so it was inevitable that the night-time interventions for our autistic child fell to me. Sleep deprivation made me very ill, and I spent a year off my job as a teacher. When I returned, it was to retrain as a special needs teacher.

By the time Ned was five I was giving him a personalised curriculum. My role very quickly became almost like that of a single father of an autistic child, while my wife became the single mother of two neuro-typical

children. It worked. Ned said his first word when he was seven, was using sentences three years later, and is now succeeding in his target of initiating social conversation.

The price I paid personally for years of 24/7 with a boy who doesn't sleep was post-traumatic stress disorder, anxiety disorder and bipolar depression. I qualified for ill-health retirement from teaching.

Mark: I see my role as reinforcing what my wife, Sam, is trying to do and to give her a break. Also, to support Rob and her. To reassure her she's doing the right thing and to keep her sane.

Simon: My wife and I both work, so there is no breadwinner/carer division of duties. We describe it more as a tag team effort. We really do split all aspects of her care 50/50 and I can't imagine why any father would want it differently.

One slight difference in our roles is that I am physically stronger than Claire, which means I can attempt things she wouldn't. For example, Mollie has a dislike of wearing shoes and walking long

distances. This meant we had to take her virtually everywhere in a stroller.

Determined to improve her mobility, I spent many Saturday mornings walking her to town and then carrying her home on my shoulders. Gradually, the walking bit got longer and the carrying bit shorter and she is now able to walk to town and back unaided. It is something I am particularly proud of.

Gavin: My role is 'dad' stuff as they're boys, so I'm more physical with them, but I don't see my role as any different to their mum's apart from that. I enjoy the fun of being with two lads, I don't really see the 'autistic' thing.

What problems have you encountered as a Dad?

Gareth: As a special needs professional, I have spent years seeing policies influenced by dismissive attitudes to fathers as either absent or deadweights, and fighting for my knowledge and experience to be acknowledged.

Mark: The problems I encounter are mainly other people's ignorance. Because he doesn't look different, when he has a meltdown it can be hard not to turn round and punch

those people who are looking on and tutting. I think I need to learn to ignore them.

Simon: There are obviously problems caused by the autism itself, but I have always been able to cope with them. What really annoys me are the 'manmade' problems that come with it. By that I chiefly mean all the battles you have to have with authority to get what your child needs. As well as coming to terms with the diagnosis you have to become an expert in autism, intervention methods, local government, disability law and benefits claims and develop rather sharp elbows overnight.

All these battles are very draining and totally unnecessary. Once you actually get access to the services you want, the support is fantastic. It just feels like you have to go through some kind of initiation test first.

Gavin: I don't have any problems being the dad of autistic children. I take Alec out to B&Q and sometimes he's let loose around the aisle and has a bit of a shout...but I find that funny. And so does he (laughs loudly). If people stare, then I really don't care. He's not behaving according to the social norms, but when you've got autistic children,

At 15 he still needs a lot of help with personal care. It's now more appropriate that his Dad is helping him.

I always put my son to bed. He goes to sleep much easier with a man's voice telling him a story or gently humming. It took us a long time to realise that he likes a deeper voice - he eventually told us that women were 'humming wrong'.



all bets are off anyway – they’re going to be different. I’m not interested in what other people think.

Has having an autistic child changed you?

Gareth: Previously, my life was measured by my achievements - since then, I have had to learn to establish a new set of priorities. It took a severe mental illness for me to realise that my work ethic was based on strictly rationed rewards for increasingly demanding workloads to achieve other people’s expectations. I’ve learned a lesson from my autistic son in that respect: it’s worth working hard for a result that improves your life experiences - but what is the point in increasing stress and pressure for someone else’s abstract goals that don’t actually change your quality of life?

“The highs are higher, the lows are lower, everything takes more effort but the rewards are greater.”

Simon Johnson

Mark: Yes. I’ve had to learn about ASC and how to deal with him and his little quirks and how they make him who he is. I am also more aware of other people with ASC because of Rob. I think it’s made me more compassionate towards others with additional needs.

Simon:

I’ve definitely changed as a person since Mollie came along but I don’t know how much of that was just down to

becoming a Dad, regardless of her autism. I think having a child with autism is a similar experience to having a child without autism, only everything gets amplified. The highs are higher, the lows are lower, everything takes more effort but the rewards are greater. There are obviously difficult times you have to go through, but something as simple as a hug or a moment’s eye contact can be overwhelmingly joyous and life affirming.

Overall, I would consider myself a better person for having a child with autism and although it isn’t a path I would have chosen, it is not something I would change now if I had the option.

Gavin: Yes, I guess. When you have boys, it’s ‘Is my kid going to be an international footballer?’ Actually, no he’s not going to be an international footballer. Absolutely no chance. And it takes the pressure off a bit, because you can just relax and see your kids for what they are. You treat them as individuals and go at their pace rather than the pace that other people set for them.

Do you have any advice for fathers who are new to autism?

Gareth: Protect your relationship with your partner above all other things. I have seen

15,000 members join ASDFriendly since 2003, and the proportion of marriage breakdowns is terrifying. You are entitled to regular nights out and occasional weekends without your children. Pay close attention to the mental and emotional health of all family members. No-one is unaffected when autism arrives in a family.

Mark: There’s a wealth of information out there - tap into it. If you have concerns at any time for your child, fight. Don’t be fobbed off. Speak to someone else who’s been there. There are more highs than there are lows, even if you don’t think there are at the time. Celebrate every milestone - however insignificant they are - like eating Weetabix instead of Shreddies!

“Pay close attention to the mental and emotional health of all family members. No-one is unaffected when autism arrives in a family.”

Gareth Child

Be prepared for a very long and hard road ahead, but I love my son no matter what.

Simon: I don’t really know how to answer this as I don’t know if what I am doing is right or wrong! I also can’t recall receiving any advice myself. Basically

I’m winging this. I think I have managed to maintain a very positive outlook on life because I’ve never worried about what Mollie is not, only what she is. I know some parents go through a sort of grieving process when they first get a diagnosis of autism for their child, but I’ve never had that. If she is happy, healthy and continuing to develop skills that will help her in future life, then I know she is on the right path for her and that’s all that matters.

Gavin: Don’t stress about it. Don’t try and make them ‘well’ because autism is for life. Just roll with it, learn to look for the cues that your child is giving you, because they do give you cues. Make an effort to understand them and don’t try to make them fit the social norms.

Being a dad of a son with autism is just an exaggerated version of what it’s like being a dad of a neuro-typical boy. There is just the need to emphasise things a lot more.

EXTRA INFO FOR DADDIES

RESEARCH: You can view the full results from Netbuddy’s recent dads’ poll at www.netbuddy.org.uk/newsletter/dad-and-me/

BLOGS: autisticdad.blogspot.com and www.autism-daddy.blogspot.com

BOOK: *Different Dads*, by Jessica Kingsley Publishing, edited by Jill Harrison, Matthew Henderson and Rob Leonard
Paperback: £13.99 ISBN: 9781843104544

SOCIAL STORY ABOUT DAD: Mark Tubbs’ wife, Sam, is the supervisor of a pre-school in Fareham which is part of the Naval Under Fives group in Hampshire. When Rob began to show anxiety at his Dad’s comings and goings, Sam made him a book to explain about his father’s work and help him to understand that life goes on when Daddy is away. The LEA in Hampshire now uses it as a template to show other families in similar situations, whether their kids have autism or not. Sam is happy for AuKids to share the book. Write to [aUKidsmag@gmail.com](mailto:aukidsmag@gmail.com)

Know of any dads’ groups in your area? We didn’t have room for them here, but post them on our Facebook site!

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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



Liz Hannah

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.”



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

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



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.



The Last Word

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

Small Talk...Big Deal

As Bobby is eight and growing in social awareness, I decided it may be the time to work on the art of conversation. 'Art' is a good word for it: it's random, abstract and involves imagination. All the things that Bob finds difficult.

This occurred to me during his third 'Compare the Meerkat.com' monologue at tea time.

When Bobby was five, any talk was to be celebrated. Just three years on and we're refining chat to an art form - it's heartening to say the least.

As a sweetener I suggested ten minutes of full-on Meerkat chat at 7.30pm. But when I broached the subject of talking about other things, Bobby straightened with his Queen Victoria face.

"Oh well, I won't talk about ANYTHING, then!"

I asked him whether I'd hurt his feelings. "Yes."

"Why?"

Bobby explained that he has 'imagination bubbles' that reside in his tummy (patted it for emphasis) and take turns going up to his head for conversational purposes. The bubbles comprise Mario, Skylanders, Raving Rabbits and Meerkats. There is nothing else there. Simple.

In short, plucking an alternative out of the blue sky was like asking him to put fairy lights up the Eiffel Tower - preferable, but tricky.

This made sense. So I asked him: "What do you think my imagination bubbles are?"

Bob's face brightened. "Duran Duran!"

Embarrassing.

After further discussion about taking turns to discuss each other's 'bubbles', we've altered Bobby's star chart to reward him for finding out other people's interests. Today, he 'compared bubbles' with his girlfriend and found that despite not exactly being enamoured with Meerkats, she likes bikes, music and Horrid Henry. "Our bubbles are the same!" exclaimed Bobby in delight, overlooking her girly penchant for Hello Kitty.

So, as with everything else in autism, I have learnt not to assume that Bobby knows what's being asked of him. The art of conversation is truly a skill, though, and can be learnt like anything else.

At the other end of the scale, Bob's previously non-verbal twin Alec has just said the word 'fart'. And we couldn't be happier.



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The Springs Community, Kent: Residential care for individuals aged 16-64.

The Springs Unit, Harrow: Secure inpatient care for adult males with autism & Asperger's.

For more information on any of our services please visit www.cygnethealth.co.uk or call Cygnet Central: 0845 070 4170

For more information contact Amy Stanion, Services Coordinator
Tel: 0161 443 4060 Email: peterlawson@cygnethealth.co.uk

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Age: 9 **I have:** Autism

My family: Mum, Dad, three older sisters (Lizan, Razaw and Lana), one younger sister (Lavn) and a brand new baby brother!

School: The Birches, West Didsbury, Manchester.

I love: Blowing bubbles, playing on the iPod, showers, riding my bike, going to the park and eating Kurdish food.

I hate: Noisy places and loud people!

Me in three words: Happy, funny and active.

If I were Prime Minister: People would ride bikes everywhere all the time...