

Aukids®

Issue 19
Spring 2013
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Positive Parenting for Children with Autism Spectrum Conditions

Could It Be Magic?

Autism's Holy Grail



Sharp Shock

Our experts tackle hand-biting



Best of the Bunch

Last chance to nominate your AuKids Big 5



PLUS

BOOKS, PRIZES and a **TWO-YEAR SUBSCRIPTION** to AuKids up for grabs!

WIN A Tom Tag



We get quite a lot of products thrown our way at AuKids. We'll be honest, some of them are a bit rubbish and don't make it as far as the pages you're reading now. Occasionally though, we get something like Tom Tag, which we are more than happy to rave about.

Tom Tag, by Orkid Ideas (nothing to do with us) is a great device for promoting independence and organisational skills by helping your child to get ready for school on their own. It's a series of six sturdy coloured tags, each incorporating six spaces for plastic 'buttons' with icons on them – you choose what goes where. The stickers that you put on the buttons are designed to remind your child (whether they're verbal or not) what to get ready. Lots of stickers are supplied with the plastic buttons, but even if none of them cover what you're looking for, there's some blank spares that you can draw on.

The colourful tags, one for each weekday and one marked 'daily' are strung together with a tough fastening that can be secured to your child's bag. They even click together to stop them swinging around. What we love is that many of our kids are visual thinkers, and this uses a strength to support a possible area of weakness.

Tom Tags are £9.99. For more info go to www.orkidideas.com, call 01904 213 123, email sales@orkidideas.com. Facebook: www.facebook.com/OrkidIdeas. Twitter: @OrkidIdeas

AuKids has Tom Tags to give away to four lucky readers.

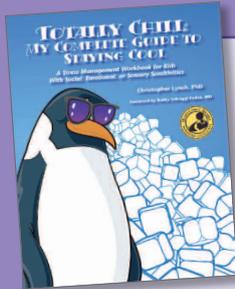
Just hunt for the rucksack hidden in the magazine. Winners will be chosen at random from entries sent before May 31st 2013. Email auidsmag@gmail.com with 'Tom Tag' in the subject header, or send your answer to AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE.

Find the Rucksack



By entering the competition you agree that your name and address will be passed onto Orkid Ideas should you be a winner, so that they can send your Tom Tag directly to you.

Reviews



BOOK Totally Chill: My Complete Guide to Staying Cool

By Christopher Lynch

Published by Autism Asperger Publishing Co

£20.50 • ISBN 9781937473044

Totally Chill: My Complete Guide to Staying Cool is a workbook for children with emotional, sensory, or social sensitivities; an issue that can often lead to stress and anxiety if children are not given the appropriate tools to cope with them. It is written in a very user-friendly way, but is not patronising. The format is perfect for working through page-by-page, or dipping into relevant sections. It first addresses how and why the child may become stressed, before tackling various strategies that the child can put into place such as developing flexible thinking, relaxation techniques, problem-solving, and organisation. Although every section may not apply to every child, the whole book focuses on

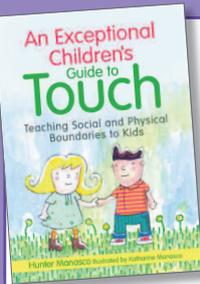
developing strengths, rather than concentrating on areas of need. Each chapter starts with explaining why the specific strategy would be useful, then achieving this using games and activities. On the completion of each chapter, the reader gets a huge pat on the back by way of 'ice blocks' to add to their 'stress management igloo', which is completed at the end in a certificate.

Overall, the book is a fantastic tool to help children learn some strategies to help them stay 'cool as a cucumber' in a somewhat confusing world.

Laura Keeling
Speech and Language
Therapist and Support Worker

WIN TOTALLY CHILL!
We have copies of *Totally Chill* to give away to two lucky readers. Ask your child to help you find the tiny penguin hidden in this issue. Send your answer to auidsmag@gmail.com with 'chill' in the subject header, or write to AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE. Winners will be drawn at random after the closing date of May 31st 2013.

Find the penguin



BOOK An Exceptional Children's Guide to Touch: Teaching Social and Physical Boundaries to Kids

By Hunter Manasco

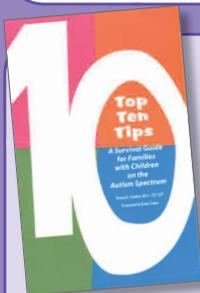
Published by Jessica Kingsley

£11.99 • ISBN 9781849058711

This brightly illustrated and simple to read book explains the different kinds of touch and what is and what is not appropriate behaviour. The book begins with

"accidental touch" and goes on to discuss "friendly touching", "hurtful touching", "touching myself", "not touching" and finally, "having my picture taken". The six chapters descriptively explain the type of touch, why it may happen and what to do if it does happen. It helpfully introduces the idea of inappropriate touch from other people and ways of staying safe without being scary or embarrassing. This is an ideal book to read and discuss with primary school children with autism and also suitable for older children.

Tori Houghton



BOOK Top Ten Tips: A Survival Guide for Families with Children on the Autism Spectrum

By Teresa A Cardon

Published by Autism Asperger Publishing Co

£16.95 • ISBN 9781934575307

A must for every family bookshelf is this one! It's like a pop-up support group at your disposal in an instant. The author has spoken to a variety of top-flight autism professionals (we recognised many of the names) and thrown in the ideas and experiences of a huge bunch of resourceful parents. Voilà, a book choc-full of Top Ten tips for virtually any subject that gets thrown your way, including eating, potty

training, travelling, birthdays, going out...you name it, it's here. With no lengthy chapters to read, but purely tips, this is just the sort of hit-me-with-it practical advice that we at AuKids love. Nicely illustrated and down to earth in style, it's one I'll not just review but no doubt use myself.

Debby Elley

WIN!
We have copies of *Top Ten Tips* to give away to three lucky readers. Simply send your name and address to us at auidsmag@gmail.com with 'Top 10' in the subject header, or send to AuKids magazine, PO Box 259, Cheadle, Cheshire SK8 9BE, clearly labelled 'Top 10'. Winners will be chosen at random after the closing date of May 31st 2013.

SAVE the Poisson Rouge website! This excellent site is great for special needs. It needs your support. Find out how at www.poissonrouge.com



Letter from the Editors



It's been a while since we've shared with our readers the reasons why we decided to start AuKids magazine. When we launched the magazine, much information available was clinical, dry and not designed for parents. As a parent of autistic twins (Debby) and highly specialist speech and language therapist (Tori), we knew full well that parents don't lose their sense of humour when they have a child with autism – in fact it's needed all the more!

Busy parents don't want to have to wade through an enormous fact file to get to the practical tip that will help them out NOW. AuKids is a world where professional experience links arms with parenting expertise, and the result we hope is advice with a good

dose of warmth and understanding.

Some of you may not know many – or any – autistic children apart from your own. Yet you're all in a similar boat, doing your best with daily challenges and not always in the most understanding of company. So we like to think of AuKids as a touchstone, that place where you truly belong.

Those fairly new to AuKids may not be aware that we do not rely on advertising to survive as a magazine, which is somewhat unusual. This gives us editorial freedom and also the liberty to promote what we choose to.

As a social enterprise, we do rely on subscriptions and some sponsorship from like-minded partners. If you are involved in a

business that's looking for a good cause, get in touch at aukidsmag@gmail.com and we'll send an information pack.

Down to other business... If you haven't already nominated us for a National Diversity Award (pretty please with blue flowers on, etc.) then don't delay, go to www.nationaldiversityawards.co.uk and nominate under the category 'community organisation' and then 'disability'. The awards panel is looking for quantity and quality of nominations.

Last but not least, we're still taking nominations for our **AuKids Big 5 Awards**. We have not yet received enough of them, so we're changing the format and giving you more time to nominate and we're also dangling a prize for encouragement! So, a **TWO-YEAR SUBSCRIPTION TO AUKIDS** will go to one lucky winner pulled from your nominations at random by June 15th. If you're already a subscriber, we'll extend your subscription by two years if you win. Or you can choose to gift the prize to someone else. Those who have

already nominated will automatically be entered. **GOOD LUCK!**

We'll shortlist and grant the awards in our summer issue. Use the slip below, post a nomination on Facebook or write to aukidsmag@gmail.com. Nominations get counted and the most popular in each category wins.

Tori & Debby

e-mail: aukidsmag@gmail.com

A warm welcome from the AuKids team goes to **David Laslett** of Manchester Creative Media, who is sponsoring us by providing our front cover photography. You can find him at www.manchesterphoto.com or email manchestercreative.media@gmail.com.



Thanks Dave, for making Phoebe's photo shoot such fun!

Competition Winners From Issue 18

Fiona Kennett, London; Rebecca Staff, Warrington; Rebecca Cave, Liverpool; Catherine Fowler-Isakpa, Stockport; F. Sephton, Liverpool; Nic Hadley, Cornwall; Afshin Tirmizi, Basingstoke; J. Quinney, Stockport; Nicola Naylor, Nuneaton and Rebecca Pullen, Newbury.

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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TEAR ALONG PERFORATION



SPEAKER

Name

Where I saw them

BOOK

Title

Author

Publisher

APP

Name of app

Designed by (company name)

PRODUCT

Name of product

Price

Available at

SENSORY TOY

Name of product

Price

Available at

Detach your nomination slip and post to AuKids Limited, PO Box 259, Cheadle, Cheshire SK8 9BE by June 15th 2013.

“ When my daughter gets anxious or excited she bites her hand. It looks painful and I don't know what to do. ”

HMMM LOVELY CHEWY SENSORY, LOVELY CHEWY SENSORY, LOVELY CHEWY...

NOT ME AGAIN!



Brenda Smith Myles Ph.D.

Brenda is an author, international speaker and award-winning consultant for the Ohio Center for Autism and Low Incidence.

As you know, your daughter is communicating her emotions (anxious or excited). Understanding why she is biting her hand is the first and major part of knowing what to do. I don't know your daughter and her communication and learning style, so the following suggestions are general:

1. Provide her with another way to communicate her feelings, such as using the Incredible 5-Point Scale, matching her emotions to facial expression or numbers. If she moves to bite her hand directly, guide her to the Scale of Emotions and a calming intervention.
2. An Occupational Therapist can provide her with items that can be used as substitutes (see other ideas on this page).
3. Consider using a social narrative (for a guide to writing Social

Stories™, see AuKids Issue 15).

4. Reinforce her for using the scale or sensory items.

5. Your daughter may need a high level of predictability in her schedule so that she feels in control. Previewing an activity verbally or looking at photos or the daily schedule helps to alleviate some of the stress of an experience. You may also want to consider having your school team work with you to develop a comprehensive plan that can teach new skills. The Ziggurat Model (see recommendations below), in my opinion, is the best comprehensive model to address this.

6. It is almost always helpful if the adults in your child's environment collaborate and share interventions. This should be considered an instructional and communication issue and a high priority.

7. Consider seeing a doctor to ensure that she does not have vitamin/mineral/nutrient deficiency or that she is processing them properly.

Brenda recommends:

1. The Incredible 5-Point Scale by Kari Dunn Buron and Mitzi Curtis
2. The Ziggurat Model: A Framework for Designing Comprehensive Interventions for High-Functioning Individuals With Autism Spectrum Disorders, Release 2.0 by Ruth Aspy and Barry Grossman
3. www.autism.org.uk/living-with-autism/understanding-behaviour/challenging-behaviour/self-injurious-behaviour.aspx



Breanne Black
BSc (Hons)

Specialist Paediatric Occupational Therapist

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Why?

Excitement and anxiety often result in the body producing a 'fight/flight' response. This is the response that occurs when your sympathetic nervous system produces hormones such as adrenaline, which assist the body to physically fight or fly when faced with perceived danger.

This is a positive function to protect you from harm. However, if maintained for lengthy periods, a heightened state of arousal like this can be counter-productive. It can exacerbate pre-existing

difficulties, like sensory sensitivities.

Self-injurious actions such as biting and head banging release serotonin, so her behaviour could calm an overly-aroused nervous system. Biting down can assist the body to calm in response to excitement or anxiety.

How Can I Help?

You can help her to replace the behaviour with something that has the same effect by encouraging 'heavy work'. This involves activities which either push joints together or pull them apart, like jumping, pushing, pulling, lifting and carrying. These are all great for proprioceptive input* and can have a calming and focusing effect. Chewing also provides proprioceptive input through the jaw.

Things you can do:

- Jumping on a trampoline, mini trampoline or Space Hopper; playing hopscotch.
- Carrying – shopping or helping with laundry.
- Pushing, pulling, doing chair push-ups and wall pushes
- Carrying a weighted backpack, or having weighted lap toys, or weighted vests and caps.



Chewigem



Squease vest



Body Sox

Useful stuff for proprioception*

Recommended by occupational therapist Breanne Black

* Proprioception is the sense of knowing where parts of our body are without vision. 'Heavy work' refers to proprioceptive input - our brains register it when we use our muscles and joints. For more information, subscribers can use our magazine archive online to refer to Issue 8.

- For the jaw, use Chew'lery (www.specialdirect.com), Chewy Tubes by Kapitex or Chewigems (www.chewigem.co.uk) Crunchy and chewy foods can also help.
- You can buy Squease Vests which fill with air (www.squeasewear.com) and other garments that exert comforting pressure like 'hug' shirts (www.sensorydirect.com)
- Deep pressure massage is good
- Stretchy toys like pilates bands (get them from any sports shop) or Body Sox (www.sensorydirect.com) can help.



Children's physiotherapist [Julia Dyer \(juliadyer.com\)](http://juliadyer.com) has kindly given us permission to reproduce some information from a recent newsletter she wrote on Oral Motor input.

Grind Force

We all use oral motor input as a tool to help regulate ourselves, and very often unconsciously. We may chew a pen, bite our nails, yawn, smoke, bite our lips or tongue or put our hands to our mouths.

Oral motor input may help us to become more alert, or it may be used to help calm us. We may use oral motor input when we are really trying to focus and concentrate.

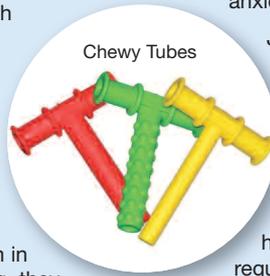
For example, watch Alex Ferguson chewing gum when Manchester United is playing.

A research study conducted in 2009 showed that when participants used chewing gum in a controlled setting, they showed significantly better alertness and reduced anxiety and stress levels.

More research has been conducted in this area and there is a growing body of research showing that chewing gum is able to increase alertness in particular.

James, for example, is constantly chewing or biting on

something, especially when he is anxious. He may bite his nails or hands. He chews the corner of his school shirt. He uses the oral motor input to try and regulate himself and lower his anxiety levels.



James now has a Chewy Tube™ which he can chew on at home and school. He also uses oral motor activities during the day to help him keep regulated and lower his anxiety levels.

Chewy Tubes™ are for children who are very strong chewers/biters. I find that they offer the most resistance. I normally purchase them from Kapitex and they are also available from many of the special needs catalogues.

Harry has a number of chewy devices. The Chewigem

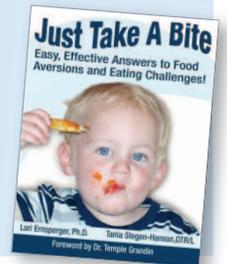
necklace seems to be the most practical one out as it's accessible when he needs it. It also looks more like a boy-type accessory. They are quite soft, though, and won't take a lot of really tough wear.

One of the main difficulties with chewing devices, especially within schools, is that they easily get lost/misplaced. Sensory Direct sell a safety lanyard which can be fixed to their Chewbuddy.

Books

Julia recommends **Just Take A Bite: Easy, Effective Answers to Food Aversions and Eating Challenges**

Foreword by Temple Grandin; authors Lori Ernsperger and Tania Stegen-Hanson. Published by Future Horizons. 9781932565124.



Chris Oliver

BSc, MPhil, PhD, CPsychol

Professor of Neurodevelopmental Disorders, School of Psychology, University of Birmingham and Cerebra Centre for Neurodevelopment Disorders.

Self-injury is shown by about 50 per cent of children and adults with autism spectrum conditions and severity varies a great deal. We know that people with ASC are more likely to show self-injury if they also have an intellectual disability.

The available research shows that there might be different causes for the self-injury and it is important to consider each before deciding how to respond and manage the behaviour.

One important possible reason is pain and discomfort and this is probably underestimated as a possible cause. Given the description provided, this seems unlikely but worth bearing in mind.

Self-injury can also occur to modulate a very high or very low state of arousal, although it still is not clear why self-injury, as opposed to any other behaviour, occurs under these circumstances.

One last and very important reason for self-injury is that the behaviour becomes a learned response because it can influence what happens next.

Dr. Caroline Richards, a PhD student at the Cerebra Centre for Neurodevelopmental Disorders, found that for six out of ten children with ASC who showed self-injury, it was a learned response.

One example is a young girl who self-injured when she heard loud noises to which she was particularly sensitive. When she heard the noise, she self-injured and then was removed from the room. Over time she had learned to communicate "Get me out of

here now!" in this way.

The intervention in this case could involve helping her to develop communication resources so that she has an equally effective but less problematic way of communicating her needs.

The important thing here is that the self-injury may have started as a response to over-arousal from the loud noise, but became communicative over time.

Research shows that if the behaviour is communicative in nature, it can increase in frequency and severity.

For this reason, psychologists would normally recommend that a functional analysis is carried out to find out if there are triggers and responses in the environment that cause the behaviour before setting up an intervention.

Dash For Cash

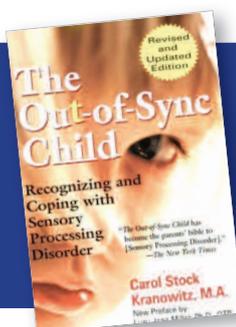
Prof. Oliver is part of a team participating in a 24-hour running event to raise money for Cerebra's fantastic work. You can donate here: www.justgiving.com/Cerebra-Centre

Did You Know...?

The charity Cerebra, which champions the needs of children with neurological conditions, has just produced a really useful leaflet on self-injurious behaviour. Look on this link to read it: www.cerebra.org.uk/English/getinformation/dailyliving/Pages/SelfInjuriousBehaviour.aspx

"If you have made attempts to avoid reinforcing the self-injury and find that the behaviour is continuing at the same level or becoming more frequent or intense then, you should contact your GP and request a referral to your local service. Due to the potential persistence of self-injury, it is important to obtain professional support as soon as it appears that attempts to reduce it have not been successful."

Cerebra's online leaflet on self-injurious behaviour



Further Info

The Out-of-Sync Child: Recognizing and Coping with Sensory Processing Disorder

By Carol Stock Kranowitz

Published by Perigee
ISBN 9780399531651

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

The views reflected in these columns are the panel's personal opinions and may not be relevant to all children with an autism spectrum condition. Parents should embark on intervention programmes only after following the advice of their child's paediatrician and/or occupational therapist.



THE SEARCH FOR THE HOLY GRAIL

When you're told your child has autism, you might feel a bit stunned. After that, it may well seem as if it's all hands on deck. Not everyone else's hands, though, they don't seem in any hurry. No, it's you who are constantly reading, researching, ringing... trying to find some answers. So why isn't anything happening fast enough?

ONE parent we spoke to, whose son is now ten, remembers the early days: "You think that every second counts. It's understandable – the diagnosis of autism is a big deal and you feel such a responsibility. But when services aren't always quick to slot into place and you feel slightly helpless and lacking in knowledge, that wait can seem endless."

Darn it, where have they hidden it?

There's also a sense that someone, somewhere, has all the answers, but they just aren't telling you.

Who has the answers?

There may be a tendency to see your paediatrician as the be-all and end-all at first. Well, they are the consultant in all things to do with childhood – they'll know what to do, right?

In fact, although your paediatrician may be initially responsible for diagnosing the autism, they are essentially a point of contact, a crossroads at which all your other professionals link up. They're also the source from which referrals are made, and the buck stops with them if professional services are not forthcoming. They aren't the person who has all the answers by any means, certainly not when it comes to practical daily strategies.

Part of finding some answers is gaining a proper understanding of

what all of the professionals connected with autism actually DO and also what you can do yourself. Professional job titles don't speak for themselves and can even be downright misleading.

Take the SLT (Speech and Language Therapist). The logical assumption is that a speech and language therapist can make your child speak. We've witnessed stutters being corrected in films like *The King's Speech* – why not the rest?

In fact, no-one can teach a child to speak when their brain isn't yet ready for it. There's plenty to be done, but verbalising itself is the icing on the cake when it comes to autism. The 'Holy Grail' in this case simply consists of a long and persistent journey.

A SLT will teach you ways to encourage the development of language in your child. Language, we need to be clear, refers not just to verbal skills but to those required to process and understand words (which can be really difficult for kids with autism) as well as to communicate with others – whether it's through signs, gestures, pictures, words or 'objects of reference' (showing them an object or part of an object to represent something else, eg. car keys to mean going out in the car).

These alternatives don't replace speech (a common misconception) but encourage it through understanding its purpose and

practice, so that when speech begins to emerge, kids are ready to use this appropriately.

When intentional sounds start to happen, then the speech and language therapist can focus on helping a child to practise, retain and perfect them.

What's Occupational Therapy?

How on earth do you know if your child needs an O.T. – (Occupational Therapist) when no-one has told you what one does? If you didn't know, you'd probably assume that these professionals helped with 'life' skills. That might be last on your list when faced with behavioural challenges on a daily basis.

For a child with autism, occupational therapy means much more than that. Occupational therapy can help them to balance their sensory needs so that their nervous system can cope with processing all the input it gets.

Sensory processing difficulties are often the cause of unusual behaviour in autism. Kids who are hyper-sensitive to sensory input may find some sounds, smells or sights quite disturbing and overwhelming. Or, your child may be under-sensitive to sensory stimulation, and some of their behaviour may be a result of that.

Brains have clever ways of compensating for confusion, and so there's usually a reason for 'odd' behaviour. Occupational therapists can help you to decipher these reasons and, through a programme which is sometimes called a 'sensory diet', can help give you and your child strategies that will help 'balance' them out.

We all learn to balance our sensory needs through external input. After a long day, you might take a bath or have a hot drink (or something

AuKids Tips For the Best Start to Your Journey:

1 Acceptance: To autistic children, people can be overwhelming. They need to learn to trust us. Acceptance is a big part of that. The more relaxed the child's environment, the more relaxed they'll be. Kids with autism are a bit like sponges when it comes to picking up on your 'vibes'.

2 Look at what bothers them: Try to understand what they don't like about their environment, even if it seems harmless to you. The less they battle with sensory issues, the more brain power is available for development and language.

3 Have fun! If an adult sits with you with a serious face and seems adamant that you do something 'just right', then pretty soon you will probably avoid that adult. So relax and enjoy whatever the child's doing, even if it doesn't seem that purposeful. For guidance, have a look at our DIY Communication Guide in our Starter's Special or look at the books at the end.

4 Take it easy: There is no deadline, despite what you may have heard. Individuals with autism are constantly blossoming. The notion that they have to speak by five to speak at all is a myth.

5 Small steps lead to large ones. Co-editor Debby says: 'Five years ago Alec wasn't communicating at all. Several years on he carried bananas upstairs to tell me he wanted one. This week, he came upstairs and whacked me gently on the shoulder with a picture card sentence that read: 'I would like the Poisson Rouge (website) please'. Progress only ever seems dramatic in hindsight.'

stronger!). If you're having trouble staying awake for a meeting, you may jog your feet or twiddle a pencil to keep yourself alert. We've all learned to control our level of alertness and our nervous system by doing these things automatically. An occupational therapist teaches our kids how to control their nervous systems on a grander scale using physical activity to calm or to alert them.

But why does all this seem to take so long?

The word 'intervention' is also very misleading! It implies that some wise chemist somewhere is bottling up a giant concoction which once consumed will solve all your worries.

Intervention unfortunately can't make miracles happen. That doesn't mean to say it's not effective, though. These strategies lead to tiny but significant changes that will help your child's development. In the early stages a great deal of patience is required, because those changes may not immediately seem apparent to you.

Most of us are aware of the stages of ordinary development – we are used to sudden leaps. With autism, changes are far more subtle. As a parent, you learn to adjust your expectations and look at communication with a magnifying glass so that you are noticing key changes. If you're new to autism, it can take time to see things in this light and may at first feel a little dispiriting.

But keep the faith. Another mum tells us: "Day after day I'd wave to him as he left on the school bus. We'd also clap hands with him all the time. Nothing. This went on for years. Then when he was about eight, he started to wave and clap.

"It could well be that physical hobbies like cycling on a trike and swimming had improved his gross motor skills, which enabled his brain to focus on fine motor skills. Combine that with a lot of singing time at his special school and a growing awareness of social skills and their signals...it all went into one big melting pot. So much had to slot into place before it happened. You never know what your input now might achieve in several years' time, even if it doesn't seem that much is happening."

What about those therapy programmes I've heard about?

If there really was one programme that had fantastic results for all kids with autism, you'd be told about it. There are plenty of therapy programmes, and many have strategies in common. They may have great results for some, but not for all.

We do advise you to become familiar with the techniques that suit your child before honing in on any single approach. For more

information on weighing up the science, check out our Starter's Special issue (see below). Research Autism at www.researchautism.net is also dedicated to sifting out the outlandish claims from the scientific reports worth looking at.

GREAT BOOKS

The Out-of-Sync Child Has Fun: Activities for Kids with Sensory Integration Dysfunction by Carol Stock Kranowitz



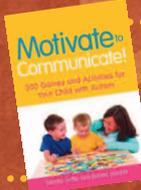
Ten Things Every Child with Autism Wishes You Knew by Ellen Notbohm

Engaging Autism: Using the Floortime Approach to Help Children Relate, Communicate, and Think by Stanley I. Greenspan and Serena Wieder



The Intensive Interaction Handbook by Dave Hewett, Mark Barber, Graham Firth and Tandy Harrison

Early Intervention Games: Fun, Joyful Ways to Develop Social and Motor Skills in Children with Autism Spectrum... by Barbara Sher



Motivate to Communicate! by Simone Griffin and Dianne Sandler

Sensory Perceptual Issues in Autism and Asperger Syndrome by Olga Bogdashina



AuKids Starter's Special

magazine can be purchased alongside a subscription or renewal, just go to www.aukids.co.uk to order one. If you can't wait to get your hands on one, send us a cheque for £5 with your name and address on the back and 'Starter's Special' written on the envelope. A guide to what's inside our Starter's Special can be found on our website.



Cygnet Health Care

Autism and Asperger's Syndrome Services



Specialised services exclusively designed to meet the needs of young people with autistic spectrum conditions and their families.

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For more information contact Saskia Little, Administrator
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Tel: 07942815845 Email: tori@time-specialist-support.com
Web: www.time-specialist-support.com



Where There's a **Will** There's a **Way**

GAVIN and I have nine year-old twins Bobby and Alec, who came with autism as a freebie. I deal with all kinds of parenting issues, but making a will has stayed firmly on the bottom of my to-do list. The idea of orphaned autistic twins is one I'd prefer not to think about. Also, the word 'legal' makes me come out in a rash. Then Tori and I figured that if I felt that way, it was a fair bet that you would, too. So, in the true spirit of camaraderie, I stepped foot inside a solicitor's office. It wasn't that painful, honest.

By Debby Elley



FROM BACK LEFT TO FRONT RIGHT: Debby, Gavin, Grandma, Grandpa, Bobby and Alec.

something on a scrap of paper that doesn't comply with the requirements of the Wills Act, then it doesn't mean anything legally. Your estate would pass in accordance with the intestacy provisions; rules that exist in the event that there's no will."

Intestacy provisions? Uh oh. Legalese hazard ahead... Fortunately, Christine also has some sort of qualification in straight talk. "Take a typical family of two parents and two kids. Intestacy rules say that if husband dies and wife survives, anything in joint names will pass to the survivor.

"After that, the first £250,000 of assets also go to the survivor. With anything in excess of that, half goes to the children outright when they reach the age of 18. The other half would be held in a life interest trust for the survivor. That means they can take the income from the asset, but the actual capital will eventually pass to the kids.

"If you've not got significant assets and everything passes to the spouse, it's not such a disaster. But if you've got more – for instance if the house was in the husband's name only and is worth £350,000 say, then you're potentially into difficulties."

There's an additional spanner in the works, Christine explains, if the wife later dies without a will. Her estate goes to all of her children outright, leaving the one (or more) with autism in a vulnerable situation. The only solution is to prepare a will.

Okay, I'm convinced. But does it mean loads of preparation? Not as much as you may think, it turns out.

"You don't need a file of bank statements and a list of exact



Hints on Choosing Your Legal Eagle

From partner
Christine Thornley, GORVINS.
Christine.Thornley@gorvins.com

- Choose a **STEP** qualified solicitor. This two-year diploma shows that a solicitor specialises in wills, trusts and estate planning.
- **MENCAP** publishes a list of solicitors they'd recommend for families like ours. Order it at www.mencap.org.uk/web-form/order-wills-and-trusts-publications
- Beware of some smaller legal firms where one lawyer does a little of everything. In the larger ones, there can be specialist branches that have a good depth of knowledge in complex wills.
- Be careful of 'cheaper' will writers, who do not have to have any formal training to practise. Some are good; some have simply signed up for a quick course.

GORVINS is South Manchester's largest law firm. It also has an established team dedicated to making wills and trusts for families who include someone with special needs. Over coffee and a Kit Kat (good start), I shared my ostrich mentality with their Wills and Trusts partner, Christine Thornley. Unfazed, she acknowledged that the 'deal with the here and now, worry about the rest later' attitude was pretty typical.

"There's so much going on in day to day life, people don't really think

.....

"If you don't know what you want in the event that anything happens to you, how on earth is anyone else going to be able to follow your wishes?"

about the future. But for parents who have children with autism, it's really more important that they do. Some children won't be able to manage money themselves; there may be a danger of them being befriended and taken advantage of for the money... So although it's difficult, in my experience, people who have prepared their wills have a massive burden lifted from their shoulders. They're not consciously thinking about it, but it's been in the back of their mind," says Christine, adding: "The overriding thing here is – if you don't know what you want in the event that anything happens to you, how on earth is anyone else going to be able to follow your wishes?"

Why not just scribble your wishes on a piece of paper at home, though?

"Firstly, a will is legally binding," says Christine. "If you just write

valuations. We just need a rough idea of how much your house is worth - no valuation needed - and any other major assets you have like savings and shares, so that we can work out whether there's an inheritance tax issue. So, roughly what you think your house is worth, who owns it and whether it's in a sole name or joint names. We don't need to know in more detail because when you die, your assets will have changed anyway."

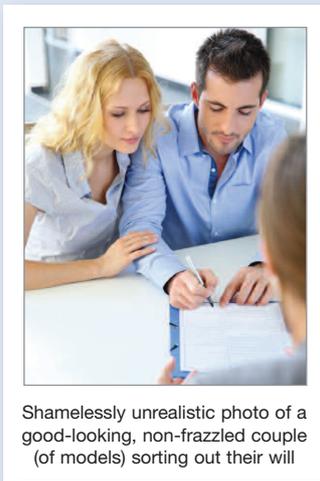
"Inherited money could affect means-tested benefits – something avoided by putting the cash into a trust."

So far, so simple. In all likelihood, though, a beneficiary with autism may need help in managing their inheritance. In this case, you'll want to build a trust into your will. Another good reason for using a trust, according to Christine, is that inherited money could affect their means-tested benefits – something avoided by putting the cash into a trust where they are listed as a potential beneficiary rather than having a direct right to the money.

Among the various types of trust available is the Disabled Person's Trust. This one gets preferential inheritance tax treatment. There are some restrictions on how it's used, though, so seek good advice before choosing it.

So, the will is sorted, the trust will be set up once you die, but one key choice is who to appoint as a trustee – the person responsible for deciding how the trust money is used. Christine agrees that it's something of a responsibility and needs to be thought about carefully.

"Some people don't want to put the responsibility on their family or are not sure they would be great at making financial decisions. But you can actually appoint a professional such as a solicitor as a trustee."



Shamelessly unrealistic photo of a good-looking, non-frazzled couple (of models) sorting out their will

Why not just leave the autistic child's share to the 'neurotypical' siblings (if they have any) to sort out for them? "We get asked that a lot. You can do, but they aren't obliged to and if they go through a divorce or are declared bankrupt, they could lose part of the money as it would be seen as an asset. Plus, if they pass away, their beneficiaries may not look after your child."

The next step is to write a letter of wishes to tell the trustee exactly what your plans are for the cash. This is where you'd note why the money was in trust and what you intended it to be used for. It can be as detailed as you like, letting them know about what sort of supported living or level of independence you'd prefer, for instance, and even the interests you'd like your child to be able to pursue in future.

The biggest decision of all, one that we all dread making, is the question of who to appoint as a guardian. I suspect I'm in a similar situation to most in that my twins' grandparents are not getting any younger and other family members have their hands full with their own kids.

Christine advises that whatever you decide is not legally binding in case today's sound decision turns out to be inappropriate in future. "It's more an expression of your wishes. If

your family disagreed, for instance, the court would still decide in the best interests of the children."

That's good, it means that I can include wishes concerning adults that I'd choose to have contact and influence in their upbringing, even if I don't appoint them as guardians.

How much does it cost? A straightforward will is typically about £350 for a couple plus VAT. Wills including trusts are more expensive, about £800 for a couple plus VAT. A number of trade unions offer free or heavily reduced will-writing services to their members, and free/reduced probate costs for dependents.

Here's the good news: Under Cerebra's *Wills and Trusts Scheme* you can get a voucher that will fund £350 towards the cost of a will – Cerebra pay the cash directly to your appointed solicitor. To qualify, your child needs to be 16 or under, have a neurological condition (autism qualifies as one) and must be in receipt of Disability Living Allowance at the middle or high rate. Be warned, there is a waiting list at the moment for the vouchers scheme and you have to be approved for funding. Once that happens, though, you have a year to use the voucher.

For an application, call Cerebra on 0800 328 1159 or download it at www.cerebra.org.uk/English/gethelp/willsandtrusts/Pages/default.aspx

P.S. What's a Power of Attorney?

- If your child needs help in managing their bank account and financial affairs as they reach adulthood, they can grant you 'power of attorney'. You'll then have legal authority to help them and can check their bank account details etc. without being told to sling your hook by the bank.
- They can also appoint you as an attorney for their health and welfare so that you can make medical decisions on their behalf.
- If your child isn't able to understand enough to grant you power of attorney, you can apply to be their nominee – that means you can receive and manage benefits on someone else's behalf.
- If they have a lot of money to manage – such as a large inheritance – you can apply to the Court of Protection for a Deputyship Order, but it can be an expensive and lengthy process so powers of attorney are always the first port of call.

Extra Information

READ ALL ABOUT IT: Order free leaflets on writing a will, creating a trust and appointing trustees at www.mencap.org.uk/all-about-learning-disability/providing-future/wills-and-trusts/how-find-solicitor.

GOOD CALL: MENCAP also has an in-house wills and trusts solicitor, Aarti Gupta, who can offer free advice by phone or email, although MENCAP does not make wills or set up trusts.

LISTEN UP: Watch out for MENCAP's free wills and trusts seminars that take place around England, Wales and Northern Ireland.

FIND THEM: Gorvins can be found at Tiviot Dale, Stockport, and at www.gorvins.com. Email enquiries@gorvins.com or call 0161 930 5151.

FOLLOW THE BLOG! I'll be finding out first-hand what it's like to get a will and trust done at Gorvins. Over the coming months, I'll be sharing the process with you. Just follow my blog at www.aukids.co.uk

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SPARKing a New Way of Thinking



spark*

SPARK* – Self Regulation Program of Awareness and Resilience in Kids

Dr Heather MacKenzie – presented by Positive About Autism

Foresight Centre, Liverpool, 6th March 2013.

AUKIDS has a network of autism experts who, in our view, know their onions. Chris Barson, of Positive About Autism, is one of them. So when he said he was so impressed with a new programme that he was bringing its creator, Dr Heather MacKenzie, over from Canada to run some UK training, we pricked up our ears, before hopping on a train to learn more.

By Debby Elley

Lost in Translation

Dr MacKenzie began with a conundrum. This was a puzzle she'd often faced during her 40-year career as a speech and language pathologist. Time and again, she'd teach autistic kids how to do the 'right thing' in a particular situation. Sure enough, they'd be able to recount the details of what was expected of them. But when push came to shove and they found themselves facing the actual challenge in reality, there was what she calls a 'disconnect' - they weren't able to apply what they'd learnt.

Part of the reason for this 'disconnect' is that autistic people have difficulty with executive functioning – the ability to quickly translate knowledge into organised and coherent action. The outcome is that they fail to use skills and strategies they know even though they can recite the rules and what they should do. It's at this point where we often want to say, 'So why didn't you do it?' It's not a matter of desire. It's more a matter of their brains not easily translating knowledge into action.

The Creation of SPARK*

Executive functioning is a problem for those on the spectrum because connections with and within the frontal lobes of the brain, responsible for executive functioning, are affected in those with ASC (Autism Spectrum Conditions).

"What we tend to do with special needs kids is take on the job of the frontal lobes," she explained. "We organise, we instruct... we make decisions for them."

She became focused on the idea of helping these kids to bridge the gap between theory and reality.



BRAIN POWER: Do you do your child's thinking for them?

She created SPARK*; a programme to help autistic children self-regulate behaviourally, emotionally and cognitively.

This sounds complicated, but when she took us through her strategies, what quickly became clear is how simple it is. We felt like slapping our foreheads and saying 'Now, why didn't we think of that?'

She began by explaining the decision making progress that each of us undergoes when starting a piece of work. As well as having to understand the bigger picture and break it down into pieces, there's a heavy degree of impulse regulation – we

have to stop ourselves from wandering away from the task in hand.

To learn how we teach behavioural self-regulation, we played some physical, fun exercises that help children learn that they have control over their bodies - how loud their voice is and how slow and fast they can move each limb.

Working Out the Clues

Cognitive self-regulation (knowing what's needed when faced with a task) involves the ability to work out a solution from a set of clues. Using the SPARK* programme, kids are taught that in any situation there are signals to watch out for. Encouraged to interpret the purpose of an exercise for themselves, they develop more flexible thinking and the ability to transpose that thinking to new situations.



SUPER SLEUTHS: Kids on the spectrum need to search for signals in each situation

To help develop cognitive self-regulation in your child, all you have to do is to act slightly clueless and encourage them to work with you to find a solution.

At the same time, they are shown how to handle the impulses that can take them over, using a range of 'resilience' techniques. These include telling their brains what's important and what's not as well

as being aware of their body's signals and choosing to control them. The techniques often involve visual imagery, which appeal widely to kids on the spectrum. One strategy is to put thoughts into a 'box' when they get overwhelming. Another great one is visualising a shield as a defence against provocation (the words just 'bounce off').

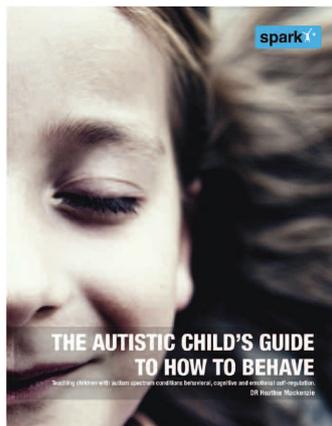
SPARK* teaches kids resilience and gives them the armour needed to deal with situations flexibly.



To help develop cognitive self-regulation in your child, all you have to do is to act slightly clueless and encourage them to work with you to find a solution. We tried it during the training with a 'pairs' puzzle. The 'adult' in our role play pretended to be unaware of what was required - it was very powerful. The "What do you think we should do here?" act allows the child to work out the clues. With a little gentle prompting and support, they learn how to learn.

After, I tried it at home with nine year-old Alec, who is non-verbal. Instead of handing him every piece of his clothing in turn, I presented him with the pile and shrugged. 'I don't know...what should we do here?'

I'll admit it was like pulling teeth, as he's used to me being the good ole frontal lobes, but eventually he handed me every piece of clothing in the right order.



I now present Bobby with puzzles rather than answers. He earns points for doing his work well at school, but was about to go on a school trip. 'How on earth are you going to earn your points outside the classroom?' I pondered.

At first, he said he didn't know. So I said I wasn't sure either. This went on for a while, until he came up with some perfect answers. I could see in his face that he was buzzing when he figured out what was needed. Within a week, he's been able to select his own clothes from the wardrobe, (with

the odd 'aren't your feet cold?' style clue), when previously I had laid them out for him.



TEAMWORK: Help your child to problem solve by taking a step back and scratching your head!

Adaptability

As a clinician, Dr MacKenzie has worked with countless kids who have profound difficulties. What I particularly like about SPARK* is that it can be adapted for any child, whatever their level of need.

Tori's response was equally enthusiastic: "A set of instructions, followed by rewards for following them, can only take you so far. Okay, so they've understood what you've said and they understand that one situation. That may be fantastic at first. But once they've achieved

that, what next? Autistic kids need the 'Why?' – it gives them motivation to work things out for themselves," she said during our post-training chat.

"As a speech and language therapist, I can see how this method helps to build on communication and interaction as well as helping with self-regulation."

As it gains popularity in schools across the pond, we believe that it's only a matter of time before the UK is set alight by SPARK*.



Some Strategies for Promoting Self-Regulation

By Speech-Language Pathologist Heather MacKenzie PhD

On a day-to-day basis, you can help every child (including those who don't have autism) improve their self-regulation skills. A few important things you can do include:

Prompting your children to think for themselves as much as possible.



This can start out very simply by providing them with simple choices ('Do you want juice or milk?'). Work towards including more things to choose between, like Debby did with her son's clothing. You can also give them choices about the order in which they prefer to do things, like go to one grocery store versus another or do maths homework before doing science homework. Doing meal planning with your children can be an effective way to improve eating habits while working on self-regulation - just remember that you can decide what things they will choose from so you can make sure the choices are healthy ones. The Eating Game (also available from Positive About Autism) provides a great structure to use for meal-planning with your children.

Explain the meaning and purpose of things you ask them to do.



Use simple, clear language to explain what you want your child to do and why it's important to do it. For example, if you are doing meal planning with your children, explain how it helps their brains and bodies work better if they eat good food or, if your children need to do homework, explain how their brains need to practise so it gets easier. These simple explanations help the children understand that there is a personal reason for doing it, giving them some ownership in the process. An example from SPARK* is when we teach the children to work systematically – we explain that it means doing one thing at a time because that way we don't miss anything.

Prompt your children to show or explain to you what they think.

I believe strongly in understanding how children with autism think about and perceive the world and people



around them. By prompting them to show or explain their thinking **without passing any judgement**, I find out so much about their thinking and also about what they learned from me. Make sure you stay open to all possibilities when you ask for your children's thoughts. They have to feel comfortable with expressing their thoughts so every idea should be treated as important and interesting. You help them with any misunderstandings and, more often than not, they may come up with a more interesting idea than yours.

Working as a partner in figuring things out with your children.

Just like Debby did, you can ask, 'What do you think we should do here?'. This approach opens



up a lot of thinking and really promotes problem-solving in your child. We need our children to be able to do this on their own in everyday life, so start with small things and keep stepping back and let your children figure things out on their own more and more.

Let your children make 'mistakes'.

It can be difficult but let your children make mistakes – they don't have to be big ones. Mistakes are opportunities for children to find out that learning is a process that takes time and practice and that mistakes are part of learning. By letting mistakes happen, your children can learn to stay alert while learning and also to become more patient with themselves.



Background to Dr Heather MacKenzie

Heather MacKenzie PhD, is a Canadian speech-language pathologist and educator who has spent a large part of her career developing and implementing approaches for enhancing learning in children with special needs. She has a special interest in understanding autism spectrum conditions. A major focus of her work with children has been on understanding them and how they approach learning and then using this knowledge to optimize their development.

She is the author of *Reaching and Teaching the Child with Autism Spectrum Disorder*, *One Story at a Time*, and *The Autistic Child's Guide to How to Behave (SPARK*)*.

To find out more, look up: www.drheathermackenzie.com

To buy the SPARK* book online or to view an interview with Heather about SPARK, go to www.positiveaboutautism.co.uk



The Last Word

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

Autism Tips from

CORONATION ST.

I wouldn't have had Sally Webster down as Coronation Street's Kofi Annan. Usually she's wading into situations with the giant spoon she used to stir the girls' beans with – that is until Rosie got bored of beans and moved away.

However, a couple of months ago, when Michelle and her (unlikely) son Ryan were seemingly rowing beyond the realms of negotiation, Sally played a blinder. With her dinner table as neutral ground, she sat them down and handed one of them the salt cellar. When that person was speaking with the salt cellar, the other had to listen. Then the salt was handed over. Eventually there was a cheerful reconciliation.

There are many games that help autistic kids to take turns in this way, but there's nothing as important in communication as taking turns when you're having a row, whether or not you're autistic.

My disagreements with Alec consist of 'No, take that out of your mouth, it's dangerous.' At the same time, I remove inanimate object, replace with more appropriate chewy thing and use Makaton signs for 'dangerous' and 'ill' whilst pointing

to his tummy. That's about it.

Bobby is more complicated. By virtue of the fact that he's verbal, anything but passive and expert at building enormous mountains out of tiny molehills, a small 'nothing' turns into a large 'something' extremely quickly.

So one day, I decided to try Sally's salt cellar method. After he'd shouted about a bit and I'd left him to it, I asked him if he wanted to feel better. Then we went into a room where it was quiet, and we brought a cuddly toy which we took turns in passing. It worked like magic, and we've used it ever since.

This has really helped him to learn that in every argument there are two sides. He's also learnt to listen, because he knows he'll get his turn to speak. Plus, it's helped us to take each objection in turn and respond to it systematically. And believe it or not, it's nipped a good few meltdowns in the bud.

So, that's my excuse for watching Corrie when I should be reading books on autism. You never know where the best hints are going to come from!



Thanks to reader Clare Calder, who wrote to us to say:

Hi. My 11 year-old son Jay has Asperger's. I've been following your page on Facebook for a while and my husband just won your two-year subscription competition. We've all enjoyed Issue 18, especially Jay. He thought the 'myths' were utterly ridiculous and seemed incensed that anyone would ever think such things! After reading the article about dogs, he asked if I could let you know about a way which he uses to help him calm down when he is sensing a meltdown... His pet snake Septimus!

He finds it useful to have Septimus with him when he's doing homework as a calming influence (especially with all the stress of SATs!) He's a bright boy who is catching up rapidly at school after lots of 'doors shut in his head' have been gently prised open.

When told that one of the editors has autistic twins, Jay said "Wouldn't it have been awful if only one of them was autistic?! It would have been much more difficult for them to understand each other!"

Because Septimus is so tame and calm, she's an ideal 'about to meltdown' companion, especially as snakes can't hear anything, they just feel vibrations!



JAY & SEPTIMUS

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COVER Star



PHOEBE SWEENEY

Age: 3

I have: The special powers of autism

Where I Live:

I live in Stockport, Cheshire, with my mum and mummy

Nursery: Charnwood Trust

I love: Bubbles, McDonald's Happy Meal, plastic bottles, rolling all over my Mummy, gingerbread men, playing in the bath, swimming and my iPad.

I hate: Quavers, chocolate and shoe shops.

Me in three words: Cheeky, clever, happy.

If I were Prime Minister: I would turn all pavements into trampolines so that I could bounce everywhere.

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