

Letter from the Editors





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

**OUTREACH SUPPORT:** For individuals aged 5-64.

**FULL TIME AND SHORT BREAK RESIDENTIAL SERVICES:** For young people aged 5-17.

**PARENT SUPPORT FORUMS:** 

Providing advice, resources and the chance to meet other parents/carers.

CYGNET'S OTHER AUTISM SERVICES INCLUDE:

Springside South West, Exeter: Outreach support services.

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: amystanion@cygnethealth.co.uk





Firstly, you'll notice the photo of a rather exhausted looking Peter Lawson of Cygnet's Springside Services, taken in a hugely sympathetic manner as he collapsed on the grass after his White Peak half-marathon in May. The AuKids team (plus Debby's twins Bobby and Alec) were there to cheer him through the finish line (with Bobby calling out every competitor's number, of course) and he made it in a hugely respectable 2 hours and 5 minutes. We're not worthy, etc... More to the point, the run raised £200 for AuKids. A massive thanks to Peter and all those who sponsored him.



If you want to run ANY event in aid of AuKids, even a coffee morning - let us know! We'd be happy to publicize it and we will encourage donations through our website. This sort of support really does help us out in a difficult climate.

Well, talking of climate...the summer generally means a lot of birthday

parties and it got us thinking about whether this is just one of those things that causes you extra stress. Certainly you can't just arrange a bash out of the blue for an autistic child. We teamed up with our friends at Netbuddy to ask parents experienced in parties for some of their best tips. And wow, they didn't disappoint! They deluged us with so much good advice that not only do you have a double page spread here, but an extra feature on our website to read at www.aukids.co.uk Bargain!

With service cuts a reality, you may be busy fighting your corner at the moment for essential intervention such as speech and language therapy. Whilst this situation is by no means what we'd want for our parents, there is still plenty you can do at home to encourage communication, even in the absence of regular sessions. Daily input from carers is so important that we decided to help out with our DIY guide. You may not be a speech and language therapist, but there's one thing you are an expert in - your child - and that goes a long way.

Don't forget to keep chatting to each other through the website and our Facebook page.

Enjoy this issue and we'll see you in the autumn!

Tori and Debby

### COMPETITION \* 🖈 | ODEON

Dimensions has teamed up with ODEON to host an autism friendly screening of Mr Popper's Penguins in cinemas across the country on August 11th at 11am. For full details, go to www.aukids.co.uk

To win tickets for a family of four, please answer the following question and get it to us by August 5th: Who stars as Mr Popper in the latest film about Mr Popper's Penguins? E-mail your answers to aukidsmag@gmail.com with full contact details.

Winner will be selected at random after the closing date. Editor's decision is final.

Our front cover star is Praj Nagarajan - see page 12.

EDITORS: PHOTOGRAPHY: PRINTING: GRAPHIC DESIGN: Tori Houghton and Debby Elley Jennie Fielden BA (Hons) Minuteman Press Stockport

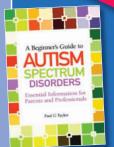


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# New Books

from Jessica Kingsley
Publishers:



A Beginner's Guide to Autism Spectrum Disorders - Essential Information for Parents and Professionals

By Paul G. Taylor £9.99
ISBN 9781849052337

What is Autism Spectrum Disorder? What does a diagnosis of ASD mean for the child and for you? How can you learn to fully understand behaviours common to ASD and help the child grow and prosper?

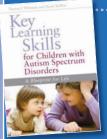
This short introduction is an ideal starting point for anyone encountering ASD for the first time. It offers effective practical strategies for assisting children who are living with ASD. It advocates putting aside conventional thinking and considering things from a different perspective - the way that the child with ASD sees the world.



Embracing Asperger's
- A Primer for Parents
and Professionals

By Richard Bromfield £12.99
ISBN 9781849058186

Parents and teachers of children with Asperger's know only too well the feeling that they are not quite reaching the child, not quite hearing or getting it, not communicating just right, or at all. Offering rich insights into what Asperger's is like for the child himself or herself, this compassionate book will empower parents and teachers, enabling them to nurture the child's strengths and work towards a happy and promising future.



Key Learning Skills for Children with Autism Spectrum Disorders - A Blueprint for Life

By Thomas L. Whitman and Nicole DeWitt £19.99
ISBN 9781849058643

Finding a way of simultaneously addressing the sensory, motor, emotional, communicative, cognitive and social needs of children on the autism spectrum can be a real challenge, and choosing from the vast array of options available is a daunting task. This book provides a blueprint for an educational intervention program that is evidence-based, comprehensive in scope and integrative in its approach.

Essential reading for families, teachers, and other professionals working with children with autism.

# Reviews



#### **BOOK**

A Friend Like Ben
- The Cat That Came
Home for Christmas

By Julia Romp
Published by HarperCollins
2010 • £14.99
ISBN 9780007376131

Reader Clara Zamborlini contacted AuKids to tell us how much she'd enjoyed reading this true story about a bond between the author's autistic son, George, and a stray cat that became part of the family. The friendship between them was so strong that it enabled her to finally make a connection with him.

The author visited Clara's autism support group in Hounslow to talk about her experiences. "She was a lovely lady," says

Clara. "You could really relate to her. Her son was so misunderstood and for many years was without a diagnosis. It was put down to him being naughty. It made me feel I was lucky to get such an early diagnosis for my daughter. You could really feel her pain and her laughter as well, because all of our kids do funny things."

Clara bought the book after seeing the author's talk. "All of the books I'd read so far were about miracle cures, usually involving spending thousands. This is the first time I picked up a book about autism and could just relax, because it was a simple and beautiful true story of someone else's experience - of the miracle of this cat, which showed her the way to get close to her son."

After the precious cat goes missing, a desperate Julia goes to extreme lengths to locate him. George and his mother's journey is an emotional and ultimately uplifting one.

#### BOOK Learni

**Learning About Friendship** 

- Stories to Support Social Skills Training in Children with Asperger Syndrome and High Functioning Autism

By K.I Al-Ghani Illustrated by Haitham Al-Ghani Published by Jessica Kingsley 2010 • £12.99 ISBN 9781849051453

Explaining the complexities of social behaviour to children with autism spectrum conditions can be challenging. This illustrated book is aimed at

primary aged children at the higher end of the spectrum. It's written as a collection of short fictional tales that help to explain different aspects of social interaction, such as sharing, making friends and being kind. A child with autism is at the heart of each story. The book also gives suggested questions to pose to the reader to help think through the problems that each story addresses. As each challenge is figured out, it also covers a range of visual strategies designed to support understanding, such as mind maps, Social Stories™ and comic strip conversations. So, plenty

conversations. So, ple of good ideas in an imaginative and nicely illustrated format.

Missing our news page?

No need, go to www.aukids.co.uk for regular news updates.



Friendship

#### **BOOK**

It's Raining Cats and Dogs

- Looking into the Minds of People on the Autistic Spectrum

Written and published by Michael Barton 2010 • £9.99 ISBN 9780956713001

When you were last told to 'have a seat' did you relax on the sofa or consider which dining room chair to take home with you? 'It's raining cats and dogs' is written and illustrated by Michael Barton, a University Student with autism. The book was compiled while Michael

was at primary school where he often struggled with adults' use of idioms,

metaphors, colloquialisms and figurative speech. To overcome his difficulties, he would draw a picture of how he interpreted the saying and his teaching assistant would provide him with the intended meaning of the phrase. The result is a humorous book that offers an invaluable insight into the mind of someone on the spectrum, encouraging parents and professionals to consider how illogical so many of our common phrases can be. Michael's book can also be a useful reference for children and teens with high functioning autism or Asperger's.

Hanna Venton-Platz, Specialist Support Worker for young people with autism.

# Slings Arrows

#### Be the First to Review Debby's Book!

Co-Editor Debby Elley's new book, **Slings and Arrows**, is available at lulu.com. The book is a true account of the accident that happened to her son Alec in 2005, preceeding her twins' diagnosis of autism by a year. In the second part of the book she recalls the twins' diagnosis. Please email aukidsmag@gmail.com if you'd like to review the book.

## Write Your Own Review!

Send in your reviews of a book or DVD to aukidsmag@gmail.com You can also review items from your child's point of view - older children may like to write their own reviews. No more than 150 words, please.

#### **Book Worms Please Note...**

The NAS books and resources 2011/12, a new catalogue of publications from the National Autistic Society, has just been released. To request your copy, please email publications@nas.org.uk or go to www.autism.org.uk/shop.

# Ask the Experts

# MELTDOWNS

We're having real trouble managing our son's meltdowns. One minute he's sweetness and light, the next moment he is in an uncontrollable rage and won't listen to reason. His teachers are also struggling. HELP!





#### **Deborah Plummer**

Formerly clinical lead speech and language therapist at Leicester, Deborah is now an author and senior lecturer in health studies at De Montfort University, where she is programme leader for the BA (Hons) Evaluating Practice: Working with Children.

Firstly, be reassured! This is not an uncommon situation. Understanding and expressing emotions in acceptable ways is a real challenge for all children. Any child who has reached the stage of 'uncontrollable anger' that you have described will undoubtedly be beyond the point where he is able to respond to requests to listen, be calm, or to explain what the problem is. Because anger is often secondary to another emotion such as sadness, frustration, embarrassment or fear, your son is likely to be feeling confused and overwhelmed. Being out of control is a frightening experience for him.

However, there are a range of strategies that you can use which will help him learn how to regulate these overwhelming feelings. Here are some suggestions for managing extreme and sudden meltdown:

 Remain as calm as possible.
 This gives him a model to follow.

- Make sure that he is physically safe
- Slowly repeat a calming word or phrase such as "You're OK" or "I'm here". It is your tone of voice and your reassurance that is most important.
- When he is beginning to quieten you may be able to add a soothing touch.
   Obviously some children can tolerate this more easily than others.
- Try to give him some clear indication that he is succeeding in calming his anger, (a non-verbal sign "I can see you are breathing more slowly").
- When he is calm (this may take some time!) he will be more able to engage with you in problem-solving whatever it was that triggered his 'meltdown'.
- Don't forget, when you talk about this later you might be able to identify another feeling that came before the anger.
- Finally, take time to relax yourself too - it can be exhausting to cope with a child's rages!

There are many other strategies that can help your child to understand that feeling angry is OK but that there are different ways to show this. Whatever you decide works best for both of you, the work you put into helping him regulate these times of rage will be well worth it as you will be helping him to build resilience and increase his ability to understand and regulate his own emotions.



Dr Paul Holland PhD C.Psychol. AFBPsS

Paul is a Chartered Psychologist based at the Department of Psychology, City University, London.

He is also a columnist for SEN magazine - the Journal for Special Needs.

Behaviours are not random reactions, they occur for a reason, as a result of a trigger and a consequence. To alter behaviour, we need to know what these are so that they can be addressed.

'Meltdowns' are not uncommon, but the antecedents (triggers) and consequences (what happens after) are typically unique to individual people and contexts.

Firstly, let's talk about the trigger. When behaviours appear suddenly and seemingly at random, it is very frustrating. But removing ourselves and our own reactions to take note of both the environment at the time of the 'meltdown' and also how others react to it is vital.

Due to the complex nature of autism, potential triggers to behaviours are often overlooked. For example, flickering fluorescent bulbs, high-pitched noises, inadvertent changes to routine and other antecedents that WE may perceive as 'typical', could be a trigger.

So be observant of everything that happens and is in place just prior to the behaviour, such as people, time, environmental changes, tiredness or hunger - everything that can be objectively identified. After noting this on a few different occasions, the next step is to link any consistencies and respond accordingly.

Secondly, look at what happens afterwards - the consequences. Behaviours that are maintained by consequences can serve five main types of purpose for a child:

- To receive desired items do we 'give in' after a meltdown?
- Escape do we remove something as a result of the behaviour?
- 3 Avoidance do we decide not to make a typical request of the child?
- 4 Attention do they get a big fuss, even if it's a negative fuss?
- 5 Self Stimulation

For the first four, in order to modify the behaviour, we need to remove reinforcement. A word of warning - when we remove reinforcement from kids, they typically get worse for a while. You would too, if your meltdown had been successful in the past, you'd simply step it up a gear. DO NOT GIVE IN THOUGH...you will only make it worse!

With self stimulation, we often need to look at alternative ways for the required stimulation to be

Overall, what is often required is both the alteration of potential triggers alongside changing how we react.

"I feel over stimulated and then angry and sad when more stimulation comes in. This hurts, since the cup is already overflowing at this point, so there is not enough room to process everything."

"It's like a sort of earthquake in my mind happens that jumbles my thoughts and makes them race and spill out in a disorganized and unfiltered manner. Following a meltdown, it feels good for a second because my thoughts reorganize (kind of like waking up from a dream state) - then a second later it feels just dreadful when I realize it happened again and I have to deal with the repercussions."

Adult with Asperger's

# WrengPlanet.net

AuKids discussed meltdowns with the adults' Asperger's forum on the Wrongplanet site. Here's the insights they gave us:

'A meltdown should be viewed as a very positive release of pent-up frustrations. Without meltdowns, the frustrations only continue to build up to truly epic proportions.'

'Meltdowns happen at the end of a long string of stresses, so it appears like the last thing that happened in the chain caused it. It's really more like reaching a boiling point and that last event only caused the spillover.'

'Frustrations accumulate because we simply have no way of expressing or dealing with them. They simply pile up over time until it all comes out at once.'

'I need time, peace, quiet, relaxation - and the emotional outburst expressed in the meltdown itself.'

'What helps? Stimming, (repetitive movements - ed.) taking a break, breathing exercises, meditation, physical exercise, attending special interests, education to deal with daily life situations - and a calm and friendly person no matter what.'

'Neurotypicals (people without autism - ed.) need to know that many of us can handle FAR LESS stimulation than you constantly provide for us.'

# 10 55 15 40 20 25 30 35

#### **Prevention is Better Than Cure!**

Using a sand timer or a battery-operated timer to 'count down' an activity before it ends is a great way to avoid meltdowns at transition times. You'd be surprised how much a clear, visual warning can help. We love the Time Timer from Special Direct but you can also get sand timers from the same source at www.specialdirect.com



Luke Beardon

Luke is a senior lecturer in autism at The Autism Centre, Sheffield Hallam University

I think that there are four main things to take into account here:

- 1 There will always be a good reason for these meltdowns.
- Removing the cause of a meltdown is almost always a preferred option though rarely, if ever, an easy one!
- 3 While meltdowns are difficult to manage and witness, do remember that they do serve a very real purpose, often a release, which can be cathartic and beneficial to the individual.

4 High levels of emotion lead to a decreased ability to process

This last point is one I would like to expand on. The fact that he 'won't listen to reason' is very open to interpretation. Quite possibly, if he is in a high state of distress, it is more likely that he can't listen to reason. In the same way that in the highly stressful job interview you only think of the perfect answer after the interview is over, individuals with autism find processing information almost impossible when in high states of arousal.

Thus, it is almost always preferable to have the 'reasoned discussion' when the individual is calm, not when they are in meltdown mode.

Secondly, when having those discussions, try not to put a neurotypical slant on the situation. Ask yourself, whose 'reason' is it that you are referring to? If it is neurotypical reasoning, then it may make little or no sense. Similarly, telling him that there was no need to get angry is nonsense - if there really was no need, then it wouldn't have happened!



Visit www.aukids.co.uk to read more responses from our expert panel. 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.



# Further Reading

Anger Management Games for Children
By Deborah M Plummer

Published by Jessica Kingsley • ISBN 9781843106289



#### Helping Children to Cope with Change, Stress and Anxiety

- A Photocopiable Activities Book By Deborah M Plummer Published by Jessica Kingsley ISBN 9781843109600

From Anxiety to Meltdown

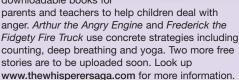
By Deborah Lipsky Published by Jessica Kingsley ISBN 9781849058438





Fire Fighting

Jennifer Anzin is an author who has worked with children with special needs for more than 25 years. Her website offers free downloadable books for



Parent Tips

"My little boy used to bash his head during a tantrum. It was really difficult to ignore, but we knew that it wasn't severe enough to harm himself, just to cause a reaction. We took away the reaction, ignored

it then rewarded him by loads of attention as soon as he stopped. Believe it or not, it worked. But I know that you can buy head protectors for kids who do this if you're worried."

"These days I find that helping my son to calm down through breathing slowly with him not only helps him to control his reactions but it also calms me down too!"

"If the meltdown happens when you're under a time constraint, it can make matters

worse as you try to 'hurry up' the calm down. My son's mainstream school knows that he's autistic. Recently l

called them up just before "If the tantrum is school to say he'd had a bad, I calmly tell him to meltdown and I was calm down and I leave him calming him down before in his room for five or ten school - they were fine minutes. It just gives me a bit and just said take your of space as well because I time. He still arrived in know that he responds to time to join assembly, it and absorbs my just gave me a few extra tension." minutes without that added

pressure. Plus he was in the right frame of mind for school."

OUR TIP: Try to avoid the combination of stresses that cause meltdowns. Look for early signals and plan in advance some anxiety calming solutions for stressful situations.

## **SUCCESS STORIES**

Mum Sylvia Johns hired a local hall with an outside area and brought a couple of big cars from home for outdoor play alongside a bubble-making machine. Inside, she arranged a Kaya drum inclusive workshop for the children.

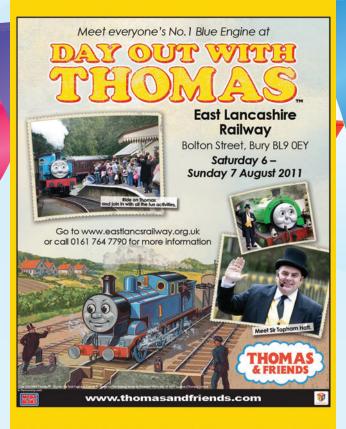
As alternatives she had Lego® and train track tables available, covered so that the kids would not initially get distracted from playing the drums. Decorations were avoided to prevent information overload. Later there was a disco, but the room was not completely dark.

"I had 16 children, 12 of them were on the spectrum and we only had happy children, not one incident, so I think we did very well!" she said.



**Debby Elley** held a party for twins Bobby and Alec at Mr Clown's Fun Zone in Hadfield, a large soft play centre which has two sensory rooms for special needs children. "Apart from the sit down tea, I kept it unstructured and allowed them to play on the big equipment - there was plenty of room and it's important not to burden autistic kids with too many expectations," she says.

Mum Fiona Hayllar held her son's fifth birthday party at a Whacky Warehouse. "I would recommend it, as for an extra £40 you can have it exclusively," she said. "It wasn't too loud, there was plenty of space, it was manageable, there wasn't loud music played through a sound system and it was safe.'



# AND I'LL FLAP

ONCE upon a time, you imagined that it'd be jelly, ice-cream and a an autistic child, a birthday party needs to be carefully adapted. www.netbuddy.org.uk to ask parents of autistic kids for their best

Get them Involved

Ask your child what kind of party they want. Which friends? Which cake? Even make invitations for their friends or family, so they feel they have some control and can take responsibility and ownership rather than having an event that is happening to them.

Date to Remember

Let the child know visually when the party is by crossing off days until the party. Prepare your child and do a verbal count down on the weeks and days to go. How far in advance you do this depends on the child - one mum said that she didn't do it until days beforehand, because her child got over-excited and had sleepless niahts.

The Magic Words

If party entertainment is part of the party, get pictures and show them to the child. Also if possible explain the rough order of the day. Get a photo of the entertainer and his name and explain what's going to happen. Remember to tell your entertainer or party planner that your child is autistic and let them know their specific needs so that they can tailor the games appropriately. For instance, telling them that their instructions must be simple.

Start Spreading the News

If you have other autistic children coming, share the details with those families. E-mail pictures or website information, or send a photo of the party venue with the invite. Also ask the parents of your guests for information on their child's particular sensory difficulties, fears and food issues.

Quiet corner On the big day, create quiet play areas or spaces away from the party for any children who get over-stimulated.

All Hands on Deck

Get your child to help out preparing for the party if possible. Even doing small jobs will help them to become aware of the reasons for the increase in

Pack Up, Ship Out!

If you feel the birthday boy/girl will be okay with the change of environment, let them stay over at a family member's house who will bring them back for the party. Mum Shashi says: 'I do this so they don't get stressed out by all the activity. My aunt looked after the boys before their fifth birthday party. They knew they were going to relax and chill out at their great aunt's house and then come back in time for the party which was really exciting for them.'

Help at Hand

If your child can't cope with an overnight stay elsewhere, have someone help out who can stay with them on the day that you are preparing for the party to occupy them or give them lunch.

Out of Sight

Clear clutter into cupboards, so that the added party paraphernalia doesn't create too much stimuli. Move any of your child's precious belongings out of reach so that other children can play without you worrying about your child having a meltdown about their special things.

Snack Survey

No matter what food you serve, make sure you have alternatives for anyone who is on restrictive diets. Find out beforehand whether other autistic guests have particular dietary requirements or won't eat certain foods. Dry finger food is less mess! less mess.

# PARTY FI WANT TO

birthday cake - DONE. Now that you have AuKids teamed up with our friends at advice. Here's what they shared...





Activities involving lots of energy help, like a sports day or mini assault course. Have calming activities, too, like bubbles.

Find your local Riding for the Disabled stables they are usually happy to run parties and you can have the club room for tea afterwards.

needs/ASD creening at the cinema.

One parent recommended using your local hydrotherapy pool - physiotherapy unit ones can sometimes be hired.

If your child is used to going to a particular club, why not suggest holding the party there? Familiar surroundings will help.

Live Music Now is a charity that brings live music to people who find it hard to access.

If you're lucky enough to live near a centre that runs inclusive trampoline sessions with experienced staff, these can make fantastic parties for autistic kids. We love Jump Space in Stockport.

If the children are sensory seekers and not frightened of balloons, hire a balloon entertainer who can model animals and flowers for them.

Mini train rides are good fun and appreciated by most autistic kids.

One parent says that sensory games work well for all children. She holds parachute games, 'pass the fibre optic' and musical statues with glow sticks!

Another parent suggests borrowing toys from lots of different friends to create added interest at home.

allow parallel play and Lego often popular with autistic

Lego® parties

kids.

Party organisers can

bring lots of

unusual small

animals for

kids to pet.

One parent realised their son much

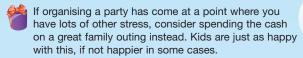
prefers to be with his therapists and carers rather than his peer group, so they make this an opportunity to have a party to say thank you to them.

## AFTERWARDS...

A lovely suggestion from this Netbuddy mum: 'Make them a little photo album of the pictures from the party or upload them on a cheap little media player. My daughter loves looking at photos and asking questions. You can use the photos to talk through what happened at the party to increase their understanding of social events.

#### AND FINALLY...

#### .A PARTY POLITICAL BROADCAST



Doing it because you did it for a sibling is faulty logic. What's right for one is not necessarily right for another. You may have to explain to siblings why the lack of a big party doesn't equal lack of love.

Despite what the playground mums say, no one will take a blind bit of notice if you don't invite 30 odd kids. Having an autistic child enables you to duck out of these daft party politics. Don't go there!

If you do go ahead with a party, make it easy and remember to have an enclosed, safe space so that you're not running after small tearaways all day.

We've got plenty more advice for you. Go to our special PARTY EXTRA feature on www.aukids.co.uk. For my Netbuddy party tips go to www.netbuddy.org.uk/get-tip/family/birthdays

With particular thanks ALL of our parents who gave us such great ideas, in particular those who gave a lot of them - Shashi Ioannides, Marie King, Sarah Hall (Willows Sensory Service), Karen Brownlee, Sylvia Johns, Fiona Hayllar and Briony Martin.

### USEFUL WEBSITE ADDRESSES

www.kayadrums.com/rhythmtherapy.html www.mrclownsfunzone.com www.livemusicnow.org.uk www.jumpspace.org.uk





## HOW TO BUILD A PATH TO COMMUNICATION

There are a multitude of different techniques for building communication. This article takes you back to basics. What happens when it's just you and your child? How do you start good interaction?

#### INSTRUCTIONS

#### STEP I DON'T SWEAT IT



Inventor Thomas Edison, (who some believe was on the autism spectrum), once said that 'genius is one percent inspiration, ninety-nine percent perspiration'. Well, in the case of speech therapy, it's vice versa. You don't have to sweat to get plenty of results, you just need to know how make use of existing opportunities.

**MYTH WATCH: ONLY TRAINED SPEECH AND LANGUAGE** THERAPISTS CAN PROVIDE THERAPY. Nope. They can guide you, but you're the one who's there to spot good opportunities. Doing a little play-based therapy daily can really help.

#### STEP 2 FIND THE RIGHT TIME AND RIGHT PLACE



Is your child in a relaxed, receptive mood? Be available. Watch, wait, listen and show that you're ready to connect. Just being fully 'there' will speak volumes.

Example: 'I find bath times a great opportunity for communication. As it's one of the few times he is in one place. I find he looks at me more. He is motivated by

the water and the bubbles and I use this as an opportunity to get him to communicate.

**MYTH WATCH:** YOU NEED A THERAPY ROOM AND A SET AMOUNT OF TIME PER DAY TO DO THERAPY. Nope. You can use your daily routine and play times to focus on targets set by occupational therapists or your speech therapist. It's about making good use of the time you already have together rather than creating lots of extra work.

#### STEP 3 PLAY DETECTIVE



Be Sherlock. Follow the child's line of sight. What has caught their interest? What need is motivating them? Just pause a second and allow them to motion or vocalise. Then you can supply the word. What would they say if they could?

For more verbal children, instead of asking questions, describe what they are doing. "You're pushing the car...." When they join in or offer a comment to the conversation, repeat it back. This lets them know that what they are saying is valued.

Example: I was getting nowhere asking my little boy questions about what he did after school. "What did you eat?" Silence. "Who did you play with?" Silence. Then one day he said he saw a DVD. I replied: "You watched a DVD?" and he said "Yes, it was Bookaboo." "Wow, Bookaboo!" "Yes..." and so on. No questions needed.



DIY TIP: You don't have to use an exciting toy. Stuff that's exciting in your view may actually be rather over-whelming to them. You can get quality interaction out of a 20p wind-up toy, a balloon, or bubbles.

#### STEP 4

#### **BREAK THE RULES**



We're used to asking children loads of questions to encourage them with play, but demands in the case of an autistic child can lead to total withdrawal.

Let the child lead the play - then they're already motivated. You've spotted the opportunity, now don't miss the chance to DO NOTHING! Look for that little signal you're welcome,

such as the child's body or eyes moving even slightly towards you. Copy what they do. Gradually, when they're happy, you can develop the game until it's a turn taking one, by handing them toys, for instance, and then asking for one in return for your 'turn'.

Example: "My child was very fascinated by some wind-up Thomas toys but couldn't operate them himself. He watched me do them whilst I was with him, then I handed one to him. He looked at me and handed it back. "Help?" I said. Then, when we raced the toys I'd repeat the word 'race' and 'winner!' Just very simple words, reinforced over and over, and it really engaged him because we had a shared focus".

#### STEP 5 BUILD TRUST



Allow the child to take the reins. To build trust you need to show your child that their play (however unconventional!) is also meaningful to you. For more verbal children, allow them to tell you what's going to happen and 'be boss'. Put them in charge of their play.

Example: "I used to spend hours showing my child how to play with the toy cars with the garage - up the lift, down the ramp etc. All he wanted to do was spin the wheels. Eventually I sat and span the wheels with him. It was at this point that I felt he truly noticed me and we were playing together!"

#### STEP 6

#### CLAMBER OVER THE BOREDOM THRESHOLD



Oh, how long those minutes can seem, when you're not 'doing' anything. You haven't made a picture, there's no glitter on the floor... Give yourself permission to just be with your child. Over time, you'll paint a far prettier picture through the relationship that develops (poetic, huh?)



DIY tip 1: Be prepared to wait for a reaction, wait for them to realise it's their turn and wait for eye contact. You'll be surprised what can happen if you tolerate a little silence and stillness.



DIY tip 2: Also, take time to think about how your child is feeling in these interactions. Is he bored? Does he want you there? He may not openly show you that he wants your involvement, but think about what he would be doing if he didn't? Allow yourself to BE in the moment with no agenda.

#### STEP 7 MIRROR THE EMOTION



If your child is calm, mirror that emotion. If excited, mirror it. If giggly and silly, go for giggly games.

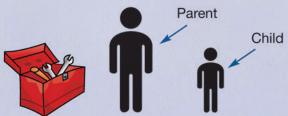
Example: "My best games are impromptu ones. The other night he was looking at a light-up toy under the duvet. Before we knew it, we had added all his light up and cuddly toys, his brother was in there too and we were having a little

tent party. I was going "Wooooooh! Spooky! Dark!" and he loved it."





## TOOL KIT YOU WILL NEED:





Show this DIY guide to other adults who your child comes into contact with. Photocopy it if You like!



LLUSTRATION BY JO PERRY, PERISCOPE STUDIOS LTD



#### STEP 8 GET DOWN WITH THE KIDS

Being on the child's level helps you to engage. Copy, mirror - you don't have to be creative. Believe in it, though. They can easily spot if you're half-hearted.

#### STEP 9 FILL IN SOME LANGUAGE



Try just copying. Or play alongside the child if you're going for a while without much connection.

For non verbal children, think about what the child is trying to communicate through his/her behaviour - e.g. when s/he hands you a toy, say: "Mummy play," or if s/he pushes a toy away "Don't want!" The more that you

respond to the communication s/he is showing you, the more s/he will understand its impact.

For the more verbal child, start by repeating what they say, then building up to using extra descriptive words. Begin to think about adding different words without changing the meanings, such as:

Child: 'Dog playing in the puddle.'

You: 'Yes, the dog is splashing in the puddle!'

Use this time to listen to what your child says and help support their language by modelling the correct grammatical structures:

Child: "Ball down the slide!"

You: "The ball is going down the slide, yes!"



DIY TIP: By modelling what he's saying, this will help him to remember appropriate sentences. With children who read and are very visual, writing the grammatically correct response may be easier for them to process.

Example: "If I really watch what he is doing and talk about it with enthusiasm and genuine interest, he listens to what I'm saying and has learnt a lot more words this way. He is also learning that there are different ways of saying the same thing.'

#### STEP 10 SEARCH FOR SIGNALS



MYTH WATCH: WE'RE LOOKING FOR SPEECH. Nope. Speech and language therapy is concerned with all aspects of communication. Only 7% of communication is words.

Example: "Once I stopped waiting for the words to come and observing his non-verbal behaviour, I realised just how much my son communicates. He will pull my hand to what he wants and turn away when I get it wrong. His body language tells me what he wants and what he is feeling. Now I know this, I know what words to put in. Because I'm not overwhelming him with words unrelated to what he's communicating, I really feel that he's listening now....'



#### DIY TIP: How do I measure success?

Think of your communication work as building a house, with verbal speech as the chimney on the roof. At the moment, you're working on the foundations, a solid connection which will be a gateway for subtle non-verbal signals, leading to more quality communication.



#### AND FINALLY...

Although Edison's first quote wasn't so relevant to us, when it comes to building communication, one other saying attributed to him was highly poignant. We'll leave you with this to ponder:



"Opportunity is missed by most people because it is dressed in overalls and looks like work."

THOMAS EDISON.

## Together for autism

Together we work across the spectrum and from birth to adulthood. The Together Trust operates residential homes, short break services (residential and fostering), supported living, Inscape House Schools, a specialist FE college and community support.

We can deliver specialist assessment, consultancy, diagnostic and speech therapy services, as well as training for parents and professionals.



#### To find out more

email enquiries@togethertrust.org.uk phone 0161 283 4848 or visit www.togethertrust.org.uk



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# **Banging the Drum** for Special Needs Theatre



OILY CART theatre company creates shows that are dramatic, colourful, musical and acrobatic. Best of all, they produce drama that's adapted especially for children with profound and multiple

learning disabilities (PMLD). This year, the company has staged performances of its latest show, Drum, specifically for children with autism. We spoke to artistic director Tim Webb to find out what inspired him to make such a huge impact through inclusive theatre.



#### Q: When did Oily Cart start up?

A: Oily Cart is 30 this year. It was formed by myself, a writer and director; Max Reinhardt, who still does the music and Claire de Loon, our designer. Originally we wanted to create theatre that was age appropriate for children under five. Ever since, we've been trying to make work that's appropriate not only to the age but also to the particular needs of the young people in our audiences.

Q: What's different about your shows?

A: Over the years, Oily Cart shows have concentrated more and more on audiences defined as PMLD or ASD. Our theatre is multisensory, appealing to every sense including the vestibular one. It is also highly interactive. We often work one-to-one so that we can respond to the various requirements of our audience members. The shows take place in

'wonderlands' - specially created spaces in which the audiences can move around with sounds, textures, aromas and sights to delight wherever you turn.

# Q: What's different about your autism-specific shows?

A: We believe that children with autism benefit from preparation before a theatre visit, so Social Stories™ are available beforehand describing the characters, the set, the story, the seating of a show, and how the child might

like to respond to it. For our latest touring show, DRUM, we also issue a time line - a strip cartoon outline of the show, so that young people with an autism spectrum condition can see where they are up to in the story.

We also think that it's important to provide a chill-out zone, where anyone who is feeling anxious or overloaded during a performance can go for a while to relax, before rejoining us.

Moveable forms of seating are also very useful in theatre for autistic audiences, providing stimulation for the vestibular sense.

We took moveable seating to an extreme in our show.

Something in the Air, where we 'flew' the audience in specially created seating, where they could experience the same movement sensations as the aerialists who worked all around them.

## Q: So what's next for Oily Cart?

A: Right now we're creating a new show, Gorgeous, all about the sense of smell. This will

begin life at the Manchester International Festival, where our show DRUM is also to be featured. Gorgeous will tour special schools in autumn, and Something In The Air will return in Spring 2012.

#### Q: And what's next for you, Tim?

A: I want to continue making challenging theatre with Oily Cart, but I also want to persuade more theatre people to make more of this much needed drama for young people with complex learning disabilities.

# What Special Schools Said About Drum:

"Very suitable for our pupils - a wonderful experience for them, cannot rate it highly enough. The sensory experience was outstanding. One parent commented that she very rarely gets an opportunity just to sit and enjoy anything with her son on her own. The experience engaged his sensory needs, which allowed them to enjoy the experience together". Linden Bridge School

"One child age four who has very fleeting attention and low arousal remained focused through both performances and was attentive and active all day (unusual for him)". Cherry Gardens School

"Great repetitive music with predictable rhythm that mesmerised all. I felt that the children loved every minute of it. The whole performance was amazing. Especially the involvement of all the children".

Richard Cloudesley School

"I observed numerous exciting and positive pupil responses: smiles, laughing, reaching out, body movements, looking...I thought 'Drum' was outstanding - it had original and effective ideas that really interested our children. I have seen many ideas that I could incorporate into my music lessons".

Woodlands School

"The music was addictive and the children really enjoyed it. They were able to focus and concentrate and then took part in all the activities". William C Harvey School



# BOBBY

# The Last Word

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

# Don't Stop **Believing**

When people ask if Alec talks, we always say *not yet*, because you never know. As far as we're concerned, it's always a possibility, just a question of when.

Alec suffered a very bad head injury when he was nearly two. It left him with complex learning difficulties on top of his autism (which wasn't at that time diagnosed) and as a result, his language centres are probably up against it.

I dislike telling people that he doesn't talk yet, though, as strangers assume that this means Alec is mute and doesn't communicate.

Actually, Alec DOES talk. Not always in a language that we understand, but he's far from mute (as grandpa, reaching for his earplugs, will testify). In fact, he's so expressive that we, like many parents of an autistic child, feel that we know him every bit as much as his verbal twin.

There's no doubt that the R2D2-style chirps, hoots, and ear-piercing screeches (not my favourite noise, I'll admit) DO mean something. Usually they're an expression of excitement or happiness, two feelings that Alec seems to be blessed with experiencing more often than most.

Also, Alec has as much non-verbal communication as anyone else, perhaps even more, or perhaps we just look for it more closely. There's the nose bounce, which means 'I'd kiss you, if I could find out how you do it'. There's the unmistakable 'I have no intention of getting up for school yet, so don't make me,' (duvet pulled over head). And then, there's the (somewhat puzzling) foot shooting out at 90 degrees whilst his hands grip the edge of the bathroom sink.

We haven't quite worked it out yet, but we think that means: 'Look! Not only can I walk now, but I am also thinking of taking up Kung Fu.'

Whilst only some of Alec's 'language' is universal, most of it can be understood by people close to him, and I wonder as I'm writing this what it is exactly that we're waiting for. Some complex expression of Alec's inner self? With all due respect to the dude, that's probably never going to happen even when language occurs. The ability to ask for things? He can do that already, using pictures. If he doesn't use pictures, he carries what he wants to me, or he points, or he pulls me.

I suppose it's just hotwired into us to expect language as a natural 'normal' milestone of development, a building block upon which undoubtedly other things will follow, as they did with his brother Robert. Until that happens, we're left wondering when it will, or if it ever will, occur.

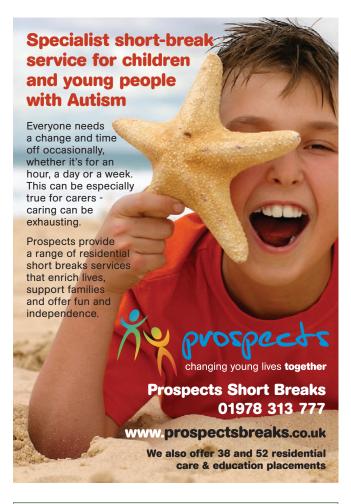
But - at one point, we didn't think Alec would walk again, let alone develop an interest in martial arts, so it's all a question of perspective where he's concerned.

In Alec's life, I've never found hope to be an underrated force. Even if what you hope for never happens, it gives you the strength and the will to try and open new doors. I've often said this before, and I truly believe this. Some of the positive spin-offs from working towards verbal communication (or building foundations, as we call it in our DIY feature) have created a truly incredible connection with Alec.

The knock on effect of all this hope should never be underestimated. Hope generates energy, energy generates fun and fun can build bonds.

So hold on to your hopes and don't let everyone else's idea of success dictate your ability to be wildly happy at the small stuff.







Specialist Babysitting, Betriending and Support Services for People with Autism

Specialist babysitting and befriending services for children and young people with Autistic Spectrum Conditions in the North West

Given the special requirements of autistic children it can be difficult to find a babysitter that you feel comfortable with, someone 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 babysitters and befrienders 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.



Tel: 07942815845 Email: tori@timebabysitting.com
Web: www.timebabysitting.com



# SPOTLICHT

Readers' Page



aged 9 Diagnosis: Autism.

School: Hermitage Primary School, Holmes Chapel, Cheshire.

Best habits: Always happy and smiling.

Worst habits: Making noises, especially high pitched ones! Switching lights on and off and knocking things over!

I love: School, books, bubbles, the beach, zoos, crazy golf, the computer, Looney Tunes and collecting DVDs

I hate: Doing as I'm told! Heights and going somewhere new, even though I usually enjoy it once I get there.

Ambition: To be a zoo keeper.

Diagnosis: Autism.

My family: Mum, dad, two year-old brother, Rishi.

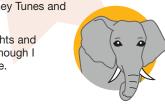
Live: Stockport.

School: Valley School in Bramhall, Cheshire - a special primary school.

I love: Playing on the computer and being outdoors. I especially enjoy swimming and I have horse riding lessons, which I love.

I hate: There's not a lot I hate! I don't like writing, colouring or painting, though.

My personality: Sweet, charming, calm, slow to anger.



Want your little star to appear on our Celebrity Spotlight page? Send your own answers with a jpeg picture of your child in action to: aukidsmag@gmail.com

# Museum Has a EUREKA! Moment

One of our favourite places to go is the National Children's Museum Eureka! in Halifax. It's thoroughly interactive and has something to appeal to kids on every level. We've recently discovered that Eureka! has weekend sessions 'A Break to Play' that support children with autism and their families. Advice is given on how to avoid sensory triggers using a sensory map of the museum. For details go to www.eureka.org.uk or call 01422 330069.

# Author Tests Out Short Story

If your child has a sibling without autism, check out www.autismuk.com/?page\_id=1475. It's a cute short story. The Diary of Samuel Pope, written by unpublished author Andrew Maddock and told from the viewpoint of an eight year old who betriends a new pupil with autism. Andrew has been working in special education for nearly 12 years and runs a drama class at Lansbury Bridge special school in 8t Helens. To contact Andrew write to andmad54@live.co.uk

#### HAPPY HOLIDAYS

Our friends at www.netbuddy.org.uk have launched an interactive holiday info pack, full of useful tips and information on holidays for people with learning disabilities, both in the UK and abroad. The pack includes information about many different types of holiday accommodation, to suit varying budgets, tastes and requirements. Visit the website for details at www.netbuddy.orquk

At AutismBuddy.com you can download high quality printables and resources for use with children with Special Educational Needs. There's booklets, puzzles and games, flashcards, worksheets, visual timetables, activities, visual aids, social skills materials and many more.

#### FREE STUFF ONLINE

#### from www.royalmail.co.uk or over the counter. PRIZE GIVEAWAY!

they send family back home a postcard. Get them

Wahay! The Royal Mail has brought out a series

of Thomas the Tank Engine stamps! Just the

thing for Thomas fans to use on holiday when

Bust my Buffers it's Thomas!

Email your name and addresss to aukidsmag@gmail.com with THOMAS STAMPS as the subject. First picked out of the hat by August 30<sup>th</sup> will win a set of Thomas stamps!



Some great free resources for kids who may have to attend hospital are at www.widgit.com/resources/healthcare/hospital\_procedures



Sponsored by **Cygnet Health Care** studionôrth

