

Positive Parenting for Children with Autism Spectrum Conditions



Letter from the Editors

## **Positive From The Start**



# Autism: Identification, Diagnosis and the Multidisciplinary Team

A new and unique two day course focusing on assessment and diagnosis of children and young people led by Dr Greg Pasco (Institute of Education, University of London)



To express an interest, email us at info@positiveaboutautism.co.uk

#### Who should attend?

- Speech and Language Therapists Psychologists



#### Course participants will have:

- explored in a highly interactive way their own opportunities for development and service improvement
- increased their understanding and confidence with diagnostic systems and assessment tools
- explored the context in which identification, assessment and diagnosis of autism take place
- developed an action plan that's ready to implement





For more details and pricing information, visit www.positiveaboutautism.co.uk or scan the QR code with your phone.

**Positive About Autism™** 



#### **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 individuals aged 5-64.

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

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



Welcome to our summer issue and what fantastic weather we're having! We're referring to those readers who are in umbrella sales, of course. We did consider a special feature on how to build your own ark but thought there might be even more pressing matters to address.

Ok readers, gloves off, hats in the ring, gauntlet down or whatever other clothing metaphor you'd like to use... we've been nominated for a National Diversity Award under the community organisation category - disability. That is the golden gong for places and people who try to make a difference, like ours.

Now the thing is, it's not guaranteed we're shortlisted until the awards people can see that there's a load of people out there who think we make a difference. So if that's you i.e. if your life was hopelessly dull before we came hopping in waving the autism banner, then pretty please with lots of purple orchids round it, nominate us at www.nationaldiversityawards.co.uk under the category Community Organisation/disability. Nominations close on July 27th so before you file the thought away for good, pop onto the computer and give us a vote - and tell others if they're fans of AuKids,

Although we look like a very professional glossy we are still only run by a team of three people – co-editors Debby and Tori and Jo our graphic designer, with Tim helping out on distribution and events. That means that yes, even after four years, we could still do with all the help we can get and awards are great for attracting help. In this climate, keeping a not-for-profit magazine up and running is as tough as it gets, but we know that you enjoy AuKids and so we'll always fight to keep afloat.

We've got some great stuff in this issue. We like to think that we're not

just here for the practical advice but also to look after the whole family. Autistic kids don't exist in a bubble and our first feature is about the most important person of all - you! We seriously, seriously mean this. Look after yourself and the rest will follow. The mere fact that you've chosen to pick up a magazine dedicated to helping your child (albeit a fascinating, entertaining one) shows that even in your leisure time, you're prepared to put your kid first. Hey well done you, we love you for it - but don't forget that you also need to remember to look after No.1.

Having taken time to reflect on yourself, we then ask you to go out into the world and change it. Just a small request, then! Yup, really, it is just a small request, honest, so read our three-page feature (with tear-out leaflet, oooooh) on how to make the world more autism friendly.

Do you ever feel like you're repeating yourself again and again...and again, to every new person who meets your child? We'll show you how making a 'passport' for them can save a lot of trouble and give your child something solid to share about themselves, even if they don't yet talk.

# Happy reading! See you in the autumn!



e-mail: aukidsmag@gmail.com

#### COMPETITION WINNERS FROM ISSUE 15:

Hannah Bowes, Manchester. Donna Cooper, Trowbridge, Wiltshire. Siobhan Fairclough, Edgware, Middlesex. Elizabeth Brassington, Kettering, Northants.

Whilst the products and services advertised in Auklids 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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## res-No **By Smarty Ears**



iPhone / iPad App £1.49

This simple app has a green smiley face on one side of the screen and a red sad face on the other side. When pressed the green face says 'yes' and the red, 'no'. There are both male and female voice options.

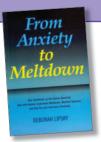
I have used this app with a teenager who has very little meaningful expressive language. Over time, however, I have realised that he understands a lot more of what is said to him than initially thought. The app has helped him to understand that when he is asked a question, he needs to respond. Two concrete choices mean that there are less words/thoughts to think about.

This app has enabled us to discuss likes and dislikes, the future and his abilities as well as what he wants to do next in the session. It has given structure to our conversation.

It's also been used by one of my colleagues with a high-functioning verbal young boy who at times is overcome by anxiety and tends to opt out of talking. Before the yes/no app was introduced, he would just look away. Now, he has the option of being able to continue engagement in the conversation when closed questions are asked. This has been really useful in finding out what he wants and what he may be finding difficult.

**Tori Houghton** 





#### **BOOK** From Anxiety to Meltdown

By Deborah Lipsky Published by Jessica Kingsley £13.99 ISBN 9781849058438 Available from www.jkp.com

This excellent book explains how anxiety causes meltdowns in autism. The author, Deborah Lipsky, has a diagnosis of autism and prides herself in being able to interpret behaviours and 'spot' potential environmental triggers. The book describes how anxiety affects cognitive ability and therefore judgement and also explains how some behaviours such as self-stimulatory ones can decrease potential rising anxiety.

She tries to explain what goes on inside the heads of children and adults with autism during a meltdown, describing possible warning signs such as humming or repetitive questioning. The book emphasises how individual these anxiety responses can be and it suggests a range of strategies to avoid meltdowns occurring, mainly involving the avoidance of sensory-related triggers.

The book is well written and informative; much of the information is a reminder of how reactions to the environment can be so different between individuals with autism and neurotypicals.

**Tori Houghton** 

# Reviews



#### **BOOK**

#### **Trueman Bradley** - Aspie Detective

By Alexei Maxim Russell Published by Jessica Kingsley £9.99 ISBN 9781849052627 Available from www.jkp.com

Aspie Detective is a frisky, easily digestible tale about small-town wannabe detective Trueman Bradley, who lands in New York eager to solve crime in the manner of his comic-book hero Slam Bradley. Naively, he assumes that it'll be a piece of cake. Despite the dangers that await him, the talented Aspie detective has an astonishing eye for detail and jaw-dropping recall for facts and figures. These, combined with his

ingenious crime-fighting equation, are formidable advantages. But Trueman, having Asperger's, also has to overcome all the sensory and social distractions that constantly threaten his equilibrium. Sometimes, they also threaten his safety. Fortunately for him, there's sidekick Dr Nora Lucca, a professional detective with oodles of patience. Together, they can outsmart even the shrewdest of criminal minds.

I'm sure the author wouldn't mind me pointing out that in style this story's more Scooby Doo than Sherlock, but if you're looking for some light-hearted fiction that beautifully - and wittily - illustrates the best advantages of Asperger's whilst vividly bringing to life its accompanying difficulties, it's a great read.

An ideal educational tool for teenagers who know someone with ASD, or are on the spectrum themselves.

Debby Elley



#### **BOOK** The Autism **Acceptance Book**

By Ellen Sabin Published by Watering Can £17.95 ISBN 9780975986820

This book is a child's guide to autism and can be used to help them to understand a classmate or relative with the condition. Its strength is that it encourages the child to use their own experiences to help them to understand life from an autistic viewpoint.

We gave the book to three children from the same family who have cousins with autism. Harry is 11, brother Jamie is 9 and Bella is 7.

Harry: "Ten out of ten, it really helped me understand autism."

Jamie: "Nine and a half, it was really good but rather repetitive."

Bella: "Ten out of ten, I thought it was brilliant and if I meet an autistic person now I know what to do.

Their dad, Daniel, told AuKids: "I thought that the content was really interesting and clear, and got the kids thinking about things for themselves about the experience of autism. This made it very easy to grasp the concepts and will be memorable too, I think.

"They really enjoyed the exercises! The only criticism I'd have was that I found the format a little bit repetitive in places. Also, I'm not sure how it is designed to be read - it's a bit of a mix of activities, reading, and group stuff. But sitting down and reading it through together was fun and worked. Only thing missing was some specific advice, like how to greet an autistic person, or how to say goodbye. Oh, and it was in American English, but we coped ok!"

With thanks to Dan, Harry, Jamie and Bella Salmons, Somerset.

**Debby Elley** 



#### **Wendy Lawson** Writer and poet

Wendy Lawson is a writer and poet who has autism. My local autism support group organised for Wendy to visit us and give a talk to an audience of 200 parents and professionals on how people with autism learn. Wendy's talk began exactly on time, and she gave us a brief insight into her personal journey of living with autism.

At school Wendy was considered 'intellectually disabled' and was misdiagnosed as 'schizophrenic' in her teens - a label which stuck for 25 years until she was diagnosed in 1994 as being on the autistic spectrum. During her talk, Wendy emphasised that to teach an individual with autism, you need to look at their learning style, personality and sensory disposition.

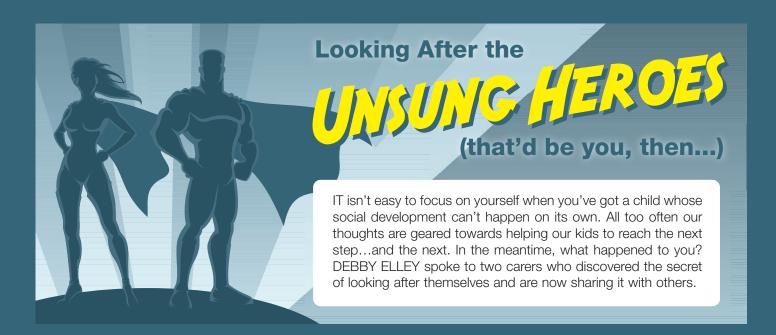
The key is to develop a connection with the autistic person through their particular interest. As everyone is unique, how we learn is also unique. Wendy went on to say that not all people with autism are visual learners, there are kinaesthetic and auditory learners also

She finished off by opening the floor for a question and answer session, making sure of course that the evening finished exactly on time!

Paula McClinton, Lisburn, County Antrim, Ireland.

The Passionate Mind: How Individuals with Autism Learn by Wendy Lawson is available from Amazon at £14.89.





### **Healthy Mind**

Geraldine Hills is the director of Inclusive Choice, a training company for parents and education professionals working with disabled children. Geraldine successfully won a landmark tribunal against her disabled son's first mainstream school and has made it her mission to make disability law easy and accessible to understand.

Parent and author Geraldine Hills knows more than anyone how carers can lose their mental wellbeing. Having emerged from a period of prolonged depression and developed a successful business, she's now started to train parent-carers to think more closely about themselves.

Her personal experience offers evidence that losing sight of your own needs can have terrible consequences.

"Sam, who is 11, has autism, septo-optic dysplasia, Tourette's and hypermobility," she says. "I think when he was very young, we were really cocooned because he was lucky enough to be in this special school where there was lots of

support. The first experience I had of mainstream was a disaster, we had to take the school to tribunal and I think I was more in shock by the way we were treated and the way Sam was treated because I was used to such love and care and support. It was like the rug was pulled out from underneath us."

Worry over Sam's school and the subsequent tribunal led Geraldine into severe depression, which wasn't recognised for some time.

"I guess from that point the worry set in, the doubt set in, the self-criticism set in - 'I must be a crap parent because apparently Sam can't cope in mainstream'. Then I was imagining 20 years ahead – he's not going to have a job, he'll never get married, no one will love him...and this was morning, noon and night."

Things went from bad to worse, with Geraldine developing agoraphobia, crying constantly and planning

"After six months of going through this, trying to put a tribunal case together, and trying to pretend I was okay, keeping the house going, cooking, being happy for Sam...I just stopped caring about myself."

The tribunal found in Geraldine's favour and was highly publicised. The whole experience, however,

made her aware of how vulnerable carers can be.

After setting up Inclusive Choice so that no other parent would face the same degree of stress when faced with unravelling the law, she has now started a course for carers to help them to reflect on their own needs.

Her main message is not to blame yourself when things go wrong. "When things go wrong it doesn't make us bad parents. If I could have talked to someone, I would have realised that Sam was happy and doing well."

"Every time you have success, it's because you chose to pick a good thought and apply it to that thing."

Geraldine's new course, How to Get What You Want Without Losing What You Already Have, has an accompanying book due to be published next year.

She explains that the course helps parent-carers to redefine who they are. "If I waved a magic wand over you and said 'Today you're having a new life, never mind about anyone else, this is just about you...' – what would you say?"

Geraldine says that the wheels of self-reflection are certainly rusty in most cases. "I wasn't ready for how hard course attendees would find thinking about what they wanted. How terrifying is it to go and get what you want when you spend all the time getting what other people need? All of a sudden, parents started owning up to being artists, writers - even a prize cake-maker! They never said – because they've never got a minute to themselves and if they have an hour, they pick up the iron."

Geraldine used her personal experiences to build on the course format. "This is not a means of

beating yourself up by setting large horizons. All you've got to do is answer one question honestly. Have I done enough today just to get myself a little bit closer towards my dream?"

What does she hope the courses will achieve?

"I hope they'll see their power. The book that I'm writing to go with the course is about shifting your focus. Every time I caught myself thinking a thought that wound me up, I'd make sure there was something else for me to do and shift my focus.

"The point is you can control the way you feel, look and react just by shifting your focus from what's wrong with you or your life to what is right and possible. Try to look at what you're grateful for – that's what got me out of the cycle of depression and moaning. Once you've shifted your focus, your mind will be clear to let that creativity back in."

Being angry and negative robs people of their personal power, according to Geraldine. "Think back to a time when you did something that blew your socks off or that you were proud of. I can guarantee it's because you were focused, you shifted your focus onto the task and you were positive about achieving it.

"I ask them on the course to take a minute to shut their eyes and think about something that they're proud of. That feeling is there, but they've forgotten it. Try this now: think of an area in your life that you are grateful for or proud of. Keep hold of that thought just for a few minutes and notice how this line of thinking





makes you feel. Do you feel different now than even just a few minutes ago? How did you breathe when you really started to think about the things you are grateful for or proud of? I bet your pulse rate went up a little or maybe even your facial expression changed. Why? Because you shifted your focus onto something good.

"You can do that for one minute a day. Good things happen when you shift your focus.

"Every time you have success, it was because you chose to pick a good thought and apply it to that thing. That's what I do now with Sam's Tourette's, when I feel a bit scared and he's been swearing in the street, I shift my focus.

"By all means have down days, have chocolate days – I don't think I could cope if every day I was singing 'Zippedy Doo Dah'! Sometimes it's too much for me. But guess what? I recognise it and I've made a choice: I will no longer be horrible to myself, I will love myself and I will care for myself. Then I can do a good job for everyone else I love, too."

For more information on Geraldine's training and to buy her books, go to www.inclusivechoice.com

## **Healthy Body**

You can't make excuses to personal trainer John Preston about how caring gets in the way of looking after yourself – he's a carer himself. John's seven year-old daughter Aimee has Rett's Syndrome. Carers, he says, are often the worst offenders when it comes to exercise.

"When I first became a single parent and full-time carer, I was three stone overweight and had to give up a really good job. Getting fit has turned my life around and benefited my family in so many different ways," he says.

In fact, he became such an advocate of fitness that he switched jobs to become a personal trainer. Having worked with people from many different walks of life, John's new company, Active Disability, will offer personal training for anyone affected by disability who wants to get healthier.

"We look at the person, not the disability. The same would apply to any client...it doesn't matter what you can't do, it's what you can do that counts."

Why does he feel that fitness is so important for carers? "I think that when you take that time to care about yourself and make the decision to get fitter, you realise that you have more physical and mental energy. This affects every other part



of your life and all of the people around you.

"Personally, I want to be around for as long as possible to play an active part in my children's lives."

He's heard every excuse imaginable. Not having time is the most common. "If you can manage 30 minutes of an activity that gets your heart racing, then you are exercising. It doesn't even have to be all in one go! Do you really not have a spare 15 minutes a couple of times per day?"

One of the excuses that makes him smile is 'I'm too unfit...'

"What? That's the point! That's the whole reason why you should be exercising!"

"Getting fit has turned my life around and benefited my family in so many different ways."

•••••

John's witnessed enough changes over the years to know the benefits of exercise can have a huge impact. "I often see clients lose three stone or three to four clothes sizes. I have a client who initially wouldn't leave the house as he perceived himself too unfit to exercise. This guy now runs over 10km per day and is doing his first Great North Run this year.

"People change from feeling tired and lethargic to energetic and lively. They no longer feel depressed or addicted to junk food and comfort eating." AuKids can vouch for this. In March this year, John asked for a volunteer. He wanted to observe how intensive exercise and a good diet over the course of a month would affect a parent-carer both mentally and physically. The results, he was sure, would be enough to convince reluctant carers to head off the sofa and into the gym.

Feeling up for the challenge, and more than slightly daunted, I put myself forward.

Through the next weeks, John and I generally fitted daily sessions into a lunch hour.

As the weeks went by, I noticed a huge mental difference. I had positive energy, focus and I had more than enough reserves for rough and tumble with the twins in the evening. My moods were lighter, too. In fact, after a month, I was buzzing so much that I knew I couldn't go back to life without regular exercise.

Most importantly, it gave me a massive boost to know that every day I was doing one thing positive for myself. When caring got tough, exercise became my precious time for some head space. When you've struggled to be patient with your kids, the tension can store up in your body. I didn't realise it until the exercise helped me to shake off that tension, making me fresher for new challenges.

Whilst a cup of coffee used to wake me up first thing, now an hour of exercise after I've done the school run wakes me up for the entire day. I did think at first I wouldn't find the time, but now I think of it as an investment for the rest of the day. Rather than wasting time, it makes me more productive.

I have never been a keen exerciser, so all this was a complete revelation to me.

My blog on the experience will be available to view when John's new website is up and running at www.activedisability.com Currently it's still under construction, but you can get advice on getting fit without breaking the bank at www.facebook.com/ActiveDisability

To contact John Preston directly, email him at info@cheshirepersonaltrainer.com

Time Specialist Support

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

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

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





#### **Further Reading**

The Selfish Pig's Guide To Caring
- How to cope with the emotional and practical aspects of caring for someone
By Hugh Marriott

Published by Piatkus • £9.99 • ISBN 9780749929862

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# Who Wants to Push the First **Domino?**

Want to change the world? So do we! We'd all love to make the world more autism friendly. At AuKids we're an impatient lot, though. Rather than wait for the world to catch on, we'd prefer to go out and change it for ourselves.

It's not that places want to be autism unfriendly. It's just that they're usually autism unaware. We can blame them for that, sure. But did you spend every day thinking about autism when it wasn't part of your life? So, who else is to blame? Us! If we don't bother to tell places how to make it easier for us, they'll continue doing what they've always done. Each of us stands to benefit by helping others to overcome ignorance.

Here's the exciting bit: if every reader pushes a single domino, making a tiny move, between us we could start a huge chain reaction. We find that thought pretty exciting.

You may have already heard of Dimensions. This not-for-profit autism services provider has already been behind initiatives such as the autism friendly cinema screenings that now take place in Odeons around the UK on a monthly basis.

Dimensions recently posted a public survey on their website to discover what types of place people would make more inclusive and why. Two hundred and fifty people took part.

"If every reader pushes a single domino, making a tiny move, between us we could start a huge chain reaction." Out of Dimensions' shortlist, restaurants were voted as the place most people would like to see made more accessible with 32% of people making it their preferred choice. Supermarkets was a close runner-up with 27% of the vote followed by leisure centres (17%), shops (10%), theatres (9%), events such as fireworks displays or sporting events (4%) and banks with 1% of the vote.

Dimensions will be using the survey results to help advise businesses on simple but effective alterations they can make to become more accessible.

Dimensions' autism lead, Executive Director of Practice Development, Lisa Hopkins, said: "There is a real need for communities to start becoming autism friendly. By setting up a poll and discussion on our website we were able to listen to people's stories about their struggles which made us realise we needed to take action. The feedback tells us that the general public need to get more informed about autism. If people took a genuine interest in what autism is, were patient, flexible, and willing to make changes, we can help them with the rest.

"We are working with businesses to become autism friendly. Readers can help by encouraging places in their local community to take part and let us know what is working for them. Support providers like Dimensions, people with autism and their supporters need to work together to truly make communities autism friendly by sharing information and learning from each other"

One place where staff are used to creating a bespoke autism-friendly environment is Autscape. Autscape is a conference run by autistic people, primarily for autistic people. We asked the Autscape team to share their main priorities for an autism-friendly setting when preparing the event.

A spokesperson told us: "First, making everything accessible without requiring social interaction, the use of speech and, whenever possible, without requiring the ability to initiate action (or at least compensating for poor ability to do so). For example, we avoid 'first come, first served' priority.

"Next, we avoid uncertainty and the need to make decisions under pressure by providing definite information in advance, such as initiation badges (these are colourcoded badges to tell other conferencegoers the level of interaction expected), information pack, schedule, and a board outside the dining room with meal choices.

"We take into account sensory issues, avoiding touch, minimising smells, flickering lights, and loud noises. Plus, everything goes at a slower pace than the neurotypical world."

That's all very well for the movers and shakers of this world, but what can you, personally, do? See the next page to find out!



# Mr Dom-In-The-Know's Guide to **Autism Friendly Outings**



We'd like to introduce you to Dom-In-The-Know. Dom knows some great ways that you can enjoy a more autism friendly experience simply by being prepared. Step one is doing all you can by following his advice. Step two is even easier. Simply tear out our leaflet, photocopy it and hand it over to places you feel would benefit. Good luck! Use our Facebook site to compare notes on how it's going and comment on places that are making an effort – let's give them our loyalty!

So, introducing an AuKids first – perforations! Now I know you don't find this very exciting, but this is the first time we've done a dotted line, so humour us will you...

#### Spot-On, Dom! Handy hints for outings



I SPY: Use photographs of the outside and inside of an outlet from the internet to prepare your child for their experience. Some places such as theatres have virtual tours online – even better. Use Google Maps to show them what the place really looks like.

MAP IT OUT: Prepare your child for a new environment with a Social Story™ about what they can expect. See Issue 15 for a guide on how to write one – new subscribers can access past issues online by going to www.aukids.co.uk and typing in their username and password.



**SCOUT ABOUT:** Before going for a meal, pop into the restaurant on another day and ask for a copy of the menu. Explain why and they should be happy to oblige. Often menus are printed on websites, or can be e-mailed to you.

GOOD CALL: Find out what adjustments can be made before you get to a place. Restaurants should be understanding with advance orders and even airports have been known to show kids about on a 'dummy' run.



WAITING GAME: Make sure your child has something to do during waiting time. Save little toys exactly for this purpose.

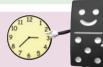
CHOOSY CUSTOMER: With the best will in the world, some places are hardly designed for children let alone autistic ones. If your child loves to run and play, choose a pub with an outside play area or a restaurant with an indoor one. Make sure the pressure is off from the start. That doesn't mean ruling out going out as a family, it just means thinking about the right place.





NOISE CRACKDOWN: If your child is over-sensitive to sudden noises, kids' ear defenders can be bought through Amazon and can make life a lot calmer. Sometimes just the thought of an unexpected sound can put a child on edge, so ear defenders offer reassurance.

PERFECT TIMING: Ok, so a place may be ruled out because it's chaos during the holidays. Sometimes that can't be helped. Don't rule it out though. Pick a school inset day, a quiet Sunday or early morning.





**OH, MY WORD!** Bring communication tools for you to make it easier for your child to express themselves. This is even more important in a new environment than at home. Bring symbol cards or a pen and a paper so that you can offer simple visual explanations.

COUNT ME IN: Get a visual timer such as the one from Special Direct.com so that your child can actually see how long they'll have to wait.





# M

#### Where's Dom?

Mr Dom-In-The-Know is hidden somewhere in this issue. Find him and be in with a chance to win four tickets to an Autism Friendly Odeon Screening anywhere in the UK in either September or October. Send your answers on a postcard to AuKids, PO Box 259, Cheadle, Cheshire, SK8 9BE or e-mail aukidsmag@gmail.com before August 20th 2012. First out of the hat wins – good luck! Usual terms and conditions apply.



presents...

How to Make Your Organisation



# **Autism**Friendly

Do your bit to make the world a better place for autistic people...at no cost!

People with autism like doing the same things as everyone else. It's just that they may have difficulty because the environments that others find easy to tolerate can be hard for them.

Autism is very common. Since autistic people often enjoy the familiar, if you make some changes you'll be certain of some loyal customers.

A lot of people with autism have difficulty with going out and about. This isn't because they don't like meeting people. It's because autism can affect the way that their brain deals with new sensory information. Distress caused by this is one of the biggest problems that people with autism face.

Smells, sights and sounds may seem overwhelming for them at times. Noisy crowds can also lead to overwhelming input. Some autistic people are sensitive to temperatures, too.





#### **Advertise**

Advertise that you're autism friendly and will accommodate different needs where possible. Ask your clients to come forward and tell you if they have an autistic person with them so that you can help if necessary. Just some understanding, tolerance and a friendly welcome is usually enough.

#### **Quiet Corner**

Have a room or area available away from noise where a child and their parent can go to calm down if things get too much.

#### **No Waiting**

People with autism find it difficult to queue. Make it clear in your publicity that they won't have to if they show you proof of Disability Living Allowance.

TEAR ALONG PERFORATION

#### **Tone It Down**

You may think that it adds to an atmosphere but some of your customers (not just autistic ones!) will find loud music intolerable. If you can't happily chat over the music, it's probably overwhelming to someone with sensory problems.

#### **Comfortable Lighting**

Try and avoid lights that are too glary. Soft lighting is best.

#### **Paper Towels**

Hand dryers are deeply unpopular with autistic people because of the sudden noise.

#### **Clear Timings**

Give a good guide beforehand to what is happening and when - point out any delays that may be encountered. This is good practise in general.

#### Take Your Cue

Parents don't expect you to know all about autism, but just take your cue from them and they'll guide you on how best to help.

#### **Visuals**

If you can have photographic or cartoon guidelines to let people know what to expect, it helps immensely with preparation, which takes anxiety out of a new situation. Make these guides available in advance by putting them on a website to download.

#### Exit

Allow autistic children to come and go and if seated, place them where this is most convenient to avoid disruption to others. Make it clear that a member of staff will escort them out if it's dark.

#### **Special Time**

Finally, if you're a place that caters especially for kids, consider having a half day open especially for children with special needs. This can take enormous pressure off parents and is often less chaotic for autistic children. Even once monthly could make a huge difference.



This guide is compiled by AuKids magazine, a positive parenting magazine for children with autism. We are run on a not-for-profit basis and rely on sponsorship and donations. To find out more or to subscribe, go to www.aukids.co.uk

If you don't want to tear this copy out of your AuKids magazine, this leaflet can be downloaded from www.dimensions-uk.org

For help and advice on autism-friendly environments, go to www.dimensions-uk.org/yourautismfriendly





#### Looking for support?



Dimensions supports people with autism to live the life they choose.

#### We provide:

- creative opportunities for children through our Buddies service
- transition support, advice and resources
- specialist behavioural support.

Get in touch to find out how we can help.



#### autism a hands on approach

**Date:** 20<sup>th</sup> November 2012. **Time:** 9.00-16.30 Venue: Stepping Hill Hospital, Stockport. Key Speakers: Dr Sue Fletcher Watson, Prof. Ann Le Couter, Charlotte Moore and Dr. Liz Pellicano. Further Details: Contact Tanya Farley on 07966 399 709.

### Together for autism

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

- Inscape House School
   Step-up course at Bridge College
  - Community support and short breaks •
  - · Shared care and full-time residential care



To find out more please contact us www.togethertrust.org.uk/services/autism enquiries@togethertrust.org.uk











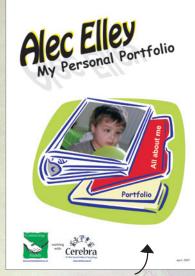
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# FIVE-STEP GUIDE TO MAKING A 'PASSPORT' FOR YOUR CHILD

(not a real one, that would be illegal)

A communication passport, sometimes called a 'personal portfolio' or 'pen picture', is a visual guide that gives preverbal children a means of sharing their own personal information such as their likes and dislikes. Using one will save you from repeating yourself to everyone who looks after your child. It will also ensure that they all have the same information and a written record that they can reference.



Here's one we did earlier, with a little help from Cerebra.

Passports do not need to be done on the computer! Cut-out pictures with written passports are just as effective.

#### Decide what's inside

Think about the information you would want someone to know if they are meeting your child for the first time - the sort of information you would pass on to someone looking after them.

Think about how your child would describe their difficulties and write the information from your child's perspective to help an adult get to know them. e.g. 'I really like watching In the Night Garden and Iggle Piggle is my favourite soft toy'.

Share the Passport with your child, they love to see themselves in print!

WEAR IT Make it into a book with a ready-made plastic spine from stationery stores and if you can, laminate it for longevity.

AB21AB21AB21AB21AB2

COPYIT

Keep several bound

copies at home so that

you can hand one over

at a moment's notice if

for instance you have a

new babysitter. Cerebra

send you several bound

versions of their version as well as a CD-Rom.

1584 ISBAISBAISBAISBAIBBAIBBA

#### Start the passport with an introduction which describes your child's difficulties from their perspective.

E.g Hi! My name is Joshua and I have autism. This means I find it hard to let people know what I want and how I feel. Even though I don't use words, I do understand simple instructions and I will try and let you know what I want by leading you to it.

Answer the following guided questions (choose those which are most appropriate to your child)

- Who do I live with and who else is important to me? (include pets)
- What school do I go to and what activities do I do out of school?
- What are the three things that I like the most how do you know?
- What are the three things that I really don't like how do I show this?
- Is there any physical/medical information that people need to know?
- How do I communicate what I want/don't want?
- What's my favourite food and what do I usually drink?
- What food do I not like?
- Is there anything about my behaviour that you would need to know?

Add photographs and visuals to support the information.

Add any important contact numbers towards the back of the booklet.



An out-of-date passport

isn't much use. Make a

note of the date that you

finished the first version,

then update annually.

## **Useful Resources**



Cerebra offer a free service helping parents to produce passports

www.cerebra.org.uk/English/gethelp/ personalportfolios/Pages/default.aspx



Experience Books is working on an online outline of the Communication Passport especially for autistic kids to show their friends. You'll be able to personalise it to their needs and create a cartoon look-alike too - it's

then professionally printed. Watch their website at www.experiencebooks.co.uk and our Facebook page (search for 'AuKids' on Facebook to find us) for further details of when it becomes available.

#### Scope to



Scope has a downloadable template which is helpful in producing your own communication passport.

www.scope.org.uk/help-andinformation/publications/ communication-passport

# Ask the Experts

My child gets really irritated by his clothes and dressing him is a real trial. Why is this and what can I do?



BSc (Hons)
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Cool For Kids Occupational Therapy www.coolforkidsoccupationaltherapy.co.uk

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Touch sensation plays an important role, which is the role of protection.

Touch can alert us to something unpleasant or dangerous. But for some, the protective function of the touch system does not work normally. A child may perceive the majority of touch to be uncomfortable or even painful and subsequently react with a 'Fight or Flight' response. We call this condition Tactile Defensiveness.

Tactile Defensiveness refers to a pattern of observable behaviour and emotional responses which are negative and out of proportion in comparison to the non-offensive response that others may give in the same situation.

For example, for the majority of people getting dressed is not a particularly uncomfortable experience. However, it may be unpleasant for someone whose touch system doesn't work accurately. Daily sensory experiences like this can make some kids fearful as a result.

#### What can you do?

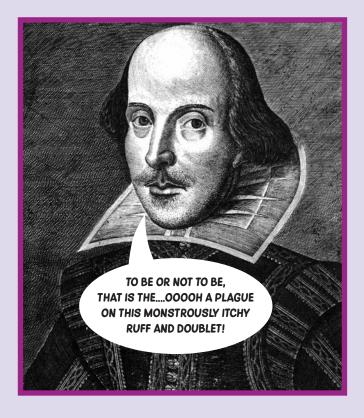
One of the most commonly used techniques is the use of deep pressure and weighted products. Deep pressure and activities which require 'heavy work' assist in calming and organising the nervous system, which in turn assists the individual to cope with tactile input. Using these activities before dressing can help to improve your child's tolerance to touch. Try:

- Application of firm pressure e.g. Hug or wrap in a towel and apply pressure.
- Deep pressure massage (can be done during washing or drying ahead of getting dressed).
- 'Heavy work' which involves pull and push forces e.g. carrying laundry and loading washing machine or clearing away the dishes.
- Pushing against a wall, chair sit ups or squeezing hands together.

#### Other general tips:

- Avoid fabrics which cause distress.
- Buy seamless socks, or turn them inside out.
- Remove labels and cover seams with a softer material.
- Tight fitting underwear made from Lycra can provide calming deep pressure.
- Use fabric softener and wash new clothes several times before they're worn.

I'd also recommend seeing an Occupational Therapist with good experience of Sensory Processing Difficulties.





**Luke Beardon** BA (Hons) PG Cert (Autism)

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

The 'why' is probably the easiest bit! It is highly likely to be sensory sensitivity, i.e. hyper-sensitivity in one or more senses. Mostly it is tactile sensitivity that causes problems in this area, but it could be other senses affected too - for example some children will not be able to tolerate strong smells (olfactory hyper-sensitivity) in which case newly washed clothes can be a problem; sometimes it is visual hypersensitivity that is the issue, in which case you will need to consider the colour, pattern, etc. of the clothes. However, it is usually the tactile (touch) sense that is the main one, so I will focus on that.

Try and identify if it is clothes in general - i.e. your child is intolerant of touch altogether - or specific areas that cause the problem. Sometimes it is the 'add-ons' that come with clothes that are the issue - the two major contenders being washing labels (cut them out) and seams in socks.

If your child simply dislikes touch and is one of those who strips off at the first opportunity, then you can try and work out what *type* of touch is the problem. For example, sometimes the light touch of clothes is intolerable, but a 'protective' layer of nice, tight undergarments (e.g. long thermal underwear) can make a huge difference.

Other aspects to consider include: does the child prefer clothes that go 'to the end' - i.e. long sleeved shirts instead of T-shirts, trousers rather than shorts? Do they like very smooth clothes, as opposed to ones broken up by buttons or zips? Lastly, shoes...they tend not to go down well at all with children with autism - so if you find a pair that suits, think ahead and, if possible, buy several larger sizes at the same time!



#### Reader Discount from Sensory Smart!

AuKids readers can claim a 10% discount on any order between now and December 31st 2012. Simply enter the promo code 10AK when ordering online at www.sensorysmart.co.uk. Offer cannot be used in conjunction with any others.



Julia Dyer MCSP BSc (Hons)

Julia is an independent children's physiotherapist and advanced sensory integration practitioner based in Clitheroe, Lancashire.

For details look up www.juliadyer.com or call 07752365487.

Children who are over-responsive to touch often have problems wearing clothes. These children register touch sensations too intensely and may even perceive touch as painful. Your child may say that the clothes hurt them. They therefore understandably do not want to wear certain clothes and are often happiest with no clothes on or may change into soft clothes such as pyjamas when they get back from school.

This is a really common problem and often becomes a battle between parents and child. A research study published in 2007 showed that 61% of children with autism were over-responsive to touch.

ERGENCE

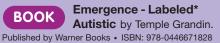
In terms of tackling the problem, the most important thing is to recognise that this is a real difficulty for your child. Do NOT make this a battleground. You need to find clothes that they are happy to wear - don't force them to wear clothes that are uncomfortable for them.

It can be difficult to find clothes and initially you may be very limited in the clothes your child will wear. I know some children who only have a few items of clothes they will wear and often refuse to wear socks and shoes.

It may be that you will need help from a therapist with qualifications in sensory integration to help you devise strategies to address the difficulties. Sensory input that is calming to the central nervous system can be used to help inhibit the over-responsive reaction. For each child, these activities will vary, but deep touch pressure, proprioception (heavy muscle work) and movement can all have a calming effect on the nervous system.

As well as using a sensory approach, the most success with children with autism will come from using a multi-faceted approach. For example, using Social Stories™, role play sessions, good communication, predictable transitions and routines.

# **Under Pressure**



Temple Grandin is one of the world's most famous and successful autistic adults. As a result of tactile defensiveness problems, she developed her own 'squeeze machine' to apply controllable pressure which was refined over the

years and is now used in therapy. In her book *Emergence – Labeled Autistic*, Temple writes: 'Tactile defensiveness behaviour and hyper-sensitivity are similar. The important thing is getting enough stimulation and it has to be relevant – the child has to know from where the stimulation is coming.'

 $^{\star}$  Eagle eyes might think we've misspelt 'labeled' but this is the US spelling.

PRODUCT
Squease vest – an inflatable pressure vest hidden inside a hooded top. Hug-like pressure is applied to the upper body simply by inflating the vest with air. It's £295 for vest, hooded top and pump, and you can rent it for a week to see if it works well before you buy. For more information go to www.squeasewear.com or call 0208 596 5461.



#### Seamless Socks & Undies for Sensitive Kids!

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Get kids dressed without the drama!!

# Sensary Smart Stare



www.sensorysmart.co.uk



Chris Barson RNMH, GWCMD Dip

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

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

In order to understand why someone with autism stands in the rain, we gotta stand in the rain with them. So, I suggest choosing a moment of privacy (front door secured and curtains closed) to get naked. Why not? We spend so much time in clothes we forget what the feel of 'no clothes' is like. It's our best shot at getting inside the experience of autism. And that is our starting point for

understanding and responding with empathy.

Thinking about our best response to this kind of problem, I'd say three things are important: choice, meaning and control.

The problem with clothes for kids with autism is often a sensory one. Clothes just drive an over-sensitive touch system crazy.

Choice Get the young person involved with what s/he wears. Maybe do some research with charity shop clothes (nicely 'broken in') to help the young person determine what for them are the least problematic. Use a rating scale and keep a chart.

Meaning What are clothes and why do we wear them? Use stories, conversation, dressing up boxes and the internet to explain and experiment. Kids love being *involved* in learning.

Control Help the young person to feel in control of their feelings and able to make sense of what they are sensing. It doesn't always have to be a problem and they can exert influence over it with support, encouragement and lots of positive feedback.

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



# The Last Word

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

# **Philosophy Made Easy**

I SHOULD CHARGE

FOR THIS!

place.

What's great about Alec? Being Alec. If you're Alec, the success of your day depends on three factors: whether you've had any cake, whether you've watched Thomas the Tank Engine and whether you've had a decent tickle session. Anything else is a bonus. He is genuinely happy most of the time and he never takes anything personally.

No-one says to me 'poor Alec' these days, and I think it's because I make it perfectly clear that he's anything but. His learning difficulties mean that Alec does not have an acquisitive nature. He does not give a monkey's whether the light-up wand I

bought him cost two quid or twenty thousand. He likes what he likes, without any regard to fashion, trends peer pressure or money.

If you take him to the zoo, Alec will prefer admiring the ducks congregating around his sandwiches (free) than the giraffes that you're desperately pointing to above his head (expensive). Why should he care? No one's pointed out to him that giraffes are more rare over here than ducks. and he wouldn't care if they did. Purely on their own merits, a greenheaded duck eating a sandwich is far more interesting than a bored looking thing with a long neck.

I allow Alec a choice of clothing in the morning and his selection is often just the most colourful and interesting top he can find. It's lovely being around someone who can't be materialistic or 'trendy' because he doesn't even know what that is.



IN THE SWING OF IT: Alec having fun, as usual

Being around Alec is a bit like being purged of the world's excesses and you can see why in some cultures special needs kids are seen as sacred. Kids like Alec don't judge and aren't aware of anyone judging them, either. If people stare at Alec when he's in full 'yodel' mode, he doesn't notice. So because he can't be offended, that's become their problem and theirs

He's in this blissful place where he takes each day as it comes and appreciates the simplest of pleasures. Nothing petty gets in the way of his enjoyment of a sunny day. He

practises the best elements of Buddhism and doesn't even know it. He doesn't grasp the meaning of the word 'grudge', and never has done. If you tell him off, it's been and gone in a second and he's your best friend again five minutes later – probably doing the same thing that got him into trouble in the first

Of course, you can focus on the fact that Alec's pretty dependent on us, and can't do a lot that we can do. But as we usually put our skills to use by getting jobs that make us stressed out and buy things we don't need, it pays to think this through a little. If you try and tell me that Alec will never be fulfilled in life, you obviously haven't seen him when faced with a selection

At the moment, Bobby is intent on finding Alec a job. He's read Mr Bump and realises that, just like Mr Bump, Alec needs to play to his strengths.

"He could be an ice-cream van man!"

"Well, there would be no ice-cream left to sell, though," Gavin pointed out.

"Hmmm. He could be a twiddly

Yes, Alec likes all things 'twiddly', so if there is such a thing as a twiddly tester, he'd be ideal. But whatever Alec does with his life, in my eyes he has already contributed something very precious. Some of the best moments in my life are the ones I share with him.

He teaches everyone around him how to live in the moment.

Scan the QR Code with your phone to go straight to our website

www.aukids.co.uk





Age: 10 | I have: Autism

School: The Birches Special Needs School, Manchester.

I love: Outdoors, zip wires, slides, twiddling, tickles, music (nursery rhymes)

I hate: Sudden loud noises, busy places.

Me in three words:

Cheeky, energetic, smiley.

If I were Prime Minister: We would travel everywhere by zip wire!!

Want your child's photo to appear in AuKids?

Send your good quality ipegs to aukidsmag@gmail.com. Photographs must be taken on a digital camera which captures at least 8 mega pixels.



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Innovation Centre

For more information on how we can help, visit our website www.cerebra.org.uk or call free on 0800 328 1159



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

studionôrth

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