



Issue 35 Spring 2017

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Positive Parenting for Children with Autism Spectrum Conditions



Letter from the Editors





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Spring into This Issue!

Hello and happy spring time! How are you? The AuKids team is doing fine. Tim Tuff our autism advocate is going from strength to strength with his one-man show. If you'd like Tim to talk at your support group, drop us a line. Tim raises funds for AuKids magazine and his talks are the result of some in-depth analysis on what makes him tick; they really are insightful.

In other news, we're also in talks with various venues to host a big comedy fundraiser towards the end of the year, when hopefully the ever-popular John Williams will return.

This Autism Awareness Month there's a couple of things you can do to help others with their understanding of autism. Alex Amelines has produced a wonderful short animation, available free, to explain autism to other kids (and it's quite good for adults too!) see if you can get your child's school to show it at assembly or in PSHE: youtu.be/7JdCY-cdgkl

AuKids has created a one page guide to making any environment autism-friendly, you can find it inside Issue 16 on our Archive at www.aukids.co.uk or if you e-mail us, we can send you a pdf. Our Autism Sundae Dessert feature is a simple way of understanding the complexities of autism for any lay person - we are taking requests now for A3 posters and if demand is high enough we'll print extra at a cost of £5 each including postage. You can find the feature in Issue 20 of our archive.

The downside of the autism friendly story is that many schools have yet to reach a level of awareness that ensures a comfortable environment for our kids. There are many conflicting demands on teaching staff and whereas it's fairly easy to be flexible in a cinema, it's much harder

to put it into practice during the school day. That said, great communication and a bit of flexibility goes a long way. Whilst supporting extra training for schools, we'd like to inspire parents to help the situation from their end. This means using the best communication possible to get your point across and help teaching staff to see what's required. Find out how in our Win-Win Schooling feature on Page 8.

Finally, help us to create future issues of AuKids. Does your child have a best buddy who isn't autistic? We want to hear from you. What do the two of them have to say about each other and their friendship? Can their parents add any extra comments about how their relationship works? All ages welcome! Just write to us at editors@aukids.co.uk We also plan to write a feature on making friends. Does your child struggle? What sort of difficulties does he or she have and what sort of advice do they and you - need? Again, write to us at editors@aukids.co.uk

See you at the end of July for our next issue!







COMPETITION WINNERS FROM ISSUE 34:

 Bittersweet on the Autism Spectrum: Diane Blood, Nottinghamshire and Marvanne Clare. Birmingham

Whilst the products and services advertised in AuKids are recommended to us by readers, we are not an industry inspector or regulator. We advise readers to seek independent advice from regulatory bodies before signing up with a new service provider and to check that products and equipment meet with industry standards

The opinions expressed in AuKids magazine are those of the contributor. Please seek medical advice before embarking on any therapy or behaviour intervention. All articles are copyright

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READERS' PAGE

Send your letters and images to editors@aukids.co.uk

Make a Date with Aukids Live!



DATE	TITLE	WHO'S TALKING?	WHERE?
27/04/17	What's it like to have autism?	Autism advocate Tim Tuff	Lisburne School, Stockport. Tickets £5.
25/05/17	Getting the best out of mainstream school	Co-editor and mum of autistic twins, Debby Elley	Time Specialist Support, Old Trafford. Tickets £5.
12/06/17	Jam on a Marmalade Day & Alec and Bobby are in the Building	Tim Tuff & Debby Elley	Hazel Grove, Stockport*. Tickets £10.
28/06/17	Keynote presentation: Alec and Bobby are in the Building	Debby Elley	Kings Park Conference and Sports Centre, Northampton†FREE
Nov 2017	My Son's Not Rainman	John Williams will return – plans in progress!	ТВА

* Hosted by Independent Options

[†]part of the FREE Equity and Social Inclusions through Positive Parenting (ESIPP) conference organised by Autism Concern

2-ALLANDON



SEARCH AUKIDS ON WWW.EVENTBRITE.CO.UK FOR DETAILS OR KEEP UP TO DATE ON FACEBOOK AND TWITTER.

Would you like an AuKids speaker? Get in touch at editors@aukids.co.uk

Toys to the Test...

AuKids is now part of a team of toy testers for Learning Resources (www.learningresources.co.uk). We will be advising them on the suitability of some of their range for children with autism. So far we've particularly liked their Magic Moves® Electronic Wand, which is a fun copying game but works on several levels as it has music and lights, too. We also liked the Playfoam® Student Set – lovely messy, sensory play without the actual mess. Doesn't stick to carpet. Result!



Cover Star



Adnan

Age: 8

Diagnosis: Autism

Lives: Manchester

Loves: Computer games, travelling anywhere on a bus, swimming - especially swimming underwater with his goggles on.

Hates: Loud noises

Both Adnan's mum and his sister describe him as 'happy all the time'. He is always very excited to go out. His support worker is always greeted by an excited Adnan!



Models Needed

A modelling and acting company is looking for children and adults with learning or physical disabilities to take part in professional photo shoots in London and Manchester during May and June. For details look on the News pages at www.aukids.co.uk or look up www.facebook.com/zebedeemanagement If interested, e-mail zebedeemanagement@gmail.com with three or four clear photos (no hats or sunglasses), contact details and a little bit about your child.

Simon Says...

Simon is a little boy who has autism. Sometimes he has to think quite hard about what to say or do next. Use our Simon cartoons as talking points with your autistic child.



Simon's mum is driving. The traffic is very bad. Simon is asking her when they are going to buy the new game he's been talking about. Mum doesn't answer. Why not?

Use this image to discuss good and bad times for asking questions. Help your child to recognise signs that you are distracted and signs that you are available.

WIN a TomTag Kit

TomTag by Orkid Ideas (www.orkidideas.com) is a quick and easy way to make personalised picture schedules, timetables and checklists. No printing, laminating or Velcro required!

With kits from the TomTag 'I can do it' range, it's a breeze to make picture checklists and sequences that help your child learn valuable independent living skills such as packing their bag for school, self care routines or managing their feelings.

For children who get anxious or confused about transitions, special events or what's going to happen next, a personalised visual schedule or timetable created with a kit from TomTag's 'I know what to expect' range can really help to reduce those anxieties and make life less stressful.

With each kit, you'll get a number of colourful tags, blank buttons, attachment loops and symbol sticker packs. There's a pick and mix option too so you can choose extra bits and bobs to add to any kit or even make your own. There's a huge range of symbols to choose from but every sticker pack includes some blank spares that you can draw on just in case you can't find exactly what you're looking for.

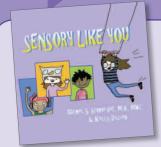
Aukids readers can enjoy a 10% discount by using **AUKIDS17** as a promotional code until July 31st 2017.

AuKids has a TomTag kit of your choice to give away to two lucky readers

Simply send your name, address and your chosen kit to competitions@aukids.co.uk with 'TomTag' in the subject header. Or write to Aukids, PO Box 259,Cheadle, Cheshire, SK8 9BE. Competition closes May 31st 2017.



Reviews & Prizes



BOOKSensory Like You

By Rachel Schneider (author) and Kelly Dillon (illustrator) Published by Future Horizons £10.50 • ISBN 9781935567707



Making Sense: A Guide to Sensory Issues by Rachel Schneider was one of our must-have reads of 2016. Now Rachel's put her good sense and easy manner to a children's book. Sensory Like You helps to inform young people with sensory issues that they're not alone. Bobby 13, who has autism including sensitive hearing, reviewed it for us:

This is a really good book for people with SPD (Sensory Processing Disorder) and autism.

The pictures are really simple and the book is really fun to read.

There are two girls in the book called Kelly and Rachel who tell you about SPD and how they see it and how it compares with things in many ways. For example, imagining having a tea party with SPD.

It also explains your different senses.

If you get this book, I hope you enjoy it because it's really simple for both you and your autistic child and many others to read.

I rate it 10/10.

Bobby Elley



BOOK

Autism Supporting
Difficulties Handbook of ideas to
reduce anxiety in
everyday situations

By Gaynor M. Jackson

Published by Matador

£8.99 • ISBN 9781785893872

We like a practical guide and Gaynor Jackson's book gets stuck in quickly with lots of strategies from an experienced advisory teacher. I felt it a pity that the opening chapter was on creating interest in books. To a parent, the timeconsuming strategies suggested may be

off-putting and this wouldn't necessarily be top of their list of things to tackle. But persevere, and use this book to dip into rather than reading it from cover to cover.

There are some brilliant tips on sharing computer time, going to dentists, doctors and hairdressers, surviving parties...in short most of the scenarios that give us nightmares. In only a hundred pages, a surprising range of topics are covered, with case studies and images to make it all easier to learn. For someone who is quite new to their child's diagnosis, this will certainly speed up your progress and could be read in just a few days. Whilst it doesn't go into any great depth, it's just what you need if you haven't had a lot of early guidance.



BOOK

All Birds Have Anxiety

By Kathy Hoopmann

Published by Jessica Kingsley
£9.99 • ISBN 9781785921827

We're usually very wary of photographic autism books as we've come across quite a few that are all style and no content. This, though, is a work of genius. Kathy Hoopmann is the best-selling author of *All Cats Have Asperger Syndrome*. In All Birds Have Anxiety, a collection of beautiful and highly amusing photographs of birds are used alongside down-to-earth, simple explanations of what anxiety is, how it affects people, our coping mechanisms and some great advice for dealing with those uncomfortable feelings.

You're not going to need to cajole a child to read this – they'll want to. Its tone avoids being patronising and it's the kind of language that kids will connect with. There aren't many words, but as a self-help resource it works so well and is suitable for any age. Our favourite page is the startled owl one, which says: 'When stress builds up, anything can set off anxiety such as:

a change of plan
something new
a comment
a thought
Stuff'

WIN A COPY!

Just email competitions@aukids.co.uk with your name and address no later than the closing date of May 31st 2017, putting 'BIRDS' in the subject header.

GOOD LUCK!



BOOK

Flying Starts for Unique Children - Top Tips for Supporting Children with SEN or Autism When They Start School

By Adele Devine
Published by Jessica Kingsley Publishers
£16.99 • ISBN 9781785920011

Adele Devine is a special needs teacher at a school for young people with severe learning difficulties and autism. This is the third of her books aimed primarily at teaching staff, but if you want a 'flying start' as a parent and need ideas around specific problem areas at school, then this is also the ideal read.

We honestly can't think of the last time we read a book addressing school issues in a way that was so comprehensive and yet so easy to navigate. Adele's clarity of thought when it comes to teaching children extends to the way that she gets her message across to her adult readers.

There are numerous ways in which this book stands out from the crowd. Adele isn't writing in an ivory tower, she is addressing difficult, real situations that require masterful problem-solving techniques and she's writing from personal experience. From the very start, she's telling it as it is, and every chapter includes inspiring case studies.

The author also sensitively and warmly discusses the feelings of parents and the importance of learning from them as well as underlining the significance of seeing a child in their home

context and learning about what motivates them.

What we really like about this handbook is its highly practical nature. It heads like a guided missile to key difficulties, unravels their root cause, then discusses a raft of no-nonsense, easy to implement strategies, following up with case studies and a summary of hints and tips. Where Adele's found other authors inspiring, she's quoted them, too.

These aren't just basic strategies, although their implementation is simple. However experienced you are, there is plenty to be gleaned by Adele's creative approaches. For instance, her visual timetables also incorporate colour-coded egg timer symbols, to give children an indication of how long an activity will last. Subjects covered include teaching waiting skills, positive behaviour approaches, toilet training, supporting kids who can't sit still, personal space, personal care, eating out - even Christmas plays!

If you work in a primary school with autistic children, whether it's mainstream or specialist, this should be compulsory reading. Read it and it will make you into an SEN Ninja Warrior.

FREE SHORT VIDEOS St Clement's Practical Autism





In March, autism trainer and education consultant Yo Dunn teamed up with St Clement's School in Dingwall to launch a series of 12 short videos on autism topics. This free resource is available online at goo.gl/Ze7v5v.

It was funded by the Scottish Government's Autism Development fund and is primarily aimed at parents, although it would also be useful for mainstream teachers supporting a pupil with autism.

Although the series is a quick tour of many key areas, the delivery is slow and deliberate, with clear graphics and simple animated cartoons to give beginners a chance to absorb some basic information about autism and helpful problem-solving strategies.

The pupils of St Clements School provide a backdrop to some sections and reinforce some of the videos' main messages.

Topics covered include a basic introduction to autism, communication (both preverbal and verbal), coping with change, diagnosis, food, sensory and social skills as well as some difficult topics such as gender ID, sexuality, mental health and school refusal.

These are handled sensibly, straightforwardly and sensitively. The sensory video in particular is a good one for training purposes, as it successfully re-creates the clamour of sensory overload.

These are useful as a starter kit and will no doubt provide much-needed support to those whose child has just received a diagnosis of autism and need some early pointers.

true

Teach Reaching Using Games™

Games make reading fun for autistic learners

Trugs was developed by teacher and phonics specialist Joanna Jeffery MBE to help inspire children to read. The system is an engaging, fun way to learn to read through card games. Trugs is based on a phonics structure that was approved by the DfE for the match-funding scheme in 2012.

Trugs Pics is great for extending the vocabulary of autistic children. Teachers have found it ideal for children on the spectrum because the games are fun and encourage social skills and turn taking without pressure. In Trugs Pics, children play finding and matching games to learn new words. There are three boxes of Trugs Pics available; Box 1 is suitable for a reading age of 6-7.5 years; Box 2 is suitable for a reading age of 7.5-9 years and box 3 is suitable for a reading age of 9-15 years.

WIN A BOX OF TRUGS PICS

For your chance to choose any of the three boxes of Trugs Pics worth £24.99 (plus VAT) each, just answer this question: How many card games are in each box of Trugs pics? You can find out at www.readsuccessfully.com

Email the answer with your name and address to Trugs directly at: tom.jeffery@readsuccessfully.com Type 'AuKids comp' in the subject header.

Closing date May 31st 2017. Winners will be contacted directly by Trugs.

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

Everything you need to know in one place www.autismlinks.co.uk



Ask the Experts



My autistic son explodes at my slightest attempt to correct him. Why...WHY?





Debby Elley & Tori Houghton

Co-editors of AuKids magazine

You see it as a teensy weensy correction. Your child, however, may be genuinely concerned that this is a BIG DEAL. What is important and what's just minor may well be a bit jumbled in his head. If he is already slightly anxious that his behaviour is different in general, then this may well confirm his worst fears about not 'fitting in'. Autistic people do tend to be rather 'black and white' in their thinking, so he may quickly judge something either perfect or a failure; the uncertainty of the 'in between' is hard to tolerate.

Failure of course leads to anxiety and autistic kids have trouble with

self-regulation when faced with uncomfortable feelings. Hence – explosion.

The first thing to tackle is the notion of perfect versus failure. Before you make corrections, let your child know that everyone makes mistakes and that this is a tiny thing. Make it clear that all people can change their behaviour and this is not the same as asking someone to change their personality.

It's an idea to grade the nature of the correction out of 10, so you're sure you're both giving it the same level of importance. Sell the solution in terms of how it will benefit them. If you can get them to think of a solution themselves (rather than imposing a 'correction') so much the better. Finally, finish with praise.

Whispering a correction as if it's a secret can arouse curiosity rather than aggravating children.

Here's an example: "I've noticed that you're pouring the Rice Krispies yourself now which is SO BRILLIANT! I've also noticed that you don't manage to get them all in the bowl, have you noticed that too? That makes quite a bit of clearing up doesn't it?

"Now, this isn't a big deal at all, it's about a 1 out of 10 in 'big deal' terms because it's only a mess, but it would be great if you were able to do that without lots of cereal on the

floor, don't you think? (Whisper) Do you want to know the secret of pouring it brilliantly? You just do it slower – that's it. How simple is that?! And when you do that, there's no mess! See how easily you did that?"

You might be thinking 'But I'm not feeling that patient when I'm wading through oceans of Cheerios and my partner is saying 'What the hell has happened here?!!' No, so that's not the right time to say something about it. Go next door, knock your head against the nearest wall, then talk about it later.

Many explosions are governed by fear of failure. They may look like anger, but are caused by pain. That's not to say don't correct, just be careful how you do it. We really believe this to be true for all children.

Extreme avoidance of any demands may be an indication of something called PDA or Pathological Demand Avoidance, which is now recognized as sometimes occurring as part of the autism spectrum. To find out more, look up www.autism.org.uk/about/what-is/pda.aspx or go to www.pdasociety.org.uk

By the way, there's a great blog on self-regulation from Curriculum Support director at Priestnall School, Gareth Morewood: blog.optimus-education.com/how-can-we-supportemotional-regulation-children-autism





Luke Beardon

Luke is a senior lecturer in autism at The Autism Centre, Sheffield Hallam University, as well as a speaker and author. Luke's Perspectives on Autism blog:

blogs.shu.ac.uk/autism

Far too many reasons to go into, but here's just one scenario:

I wake up, turn the alarm off, and get up. My alarm clock reads 7.00am; my watch, 6.54am. The clock on my wall shows just gone 7.01. Which one is correct? They can't all be right! Already, that dread feeling, that knowledge that the world is chaos, that I can't find any logic, anything to anchor me, anything to make me feel safe.

My clothes are waiting for me at the end of the bed; a challenge, a direct taunt. 'We know it hurts you to wear us...' they seem to whisper... 'but you have to anyway...'. Yes, I do. I dress, and immediately fight against the hideous sensations of my school uniform that I 'have' to wear. My brain is already aching at the energy it needs to cope.

What, what, what can I do?

I turn on my computer. I am full of a horrific mix of emotions. I know I am in the wrong; I know the rule is that I'm not allowed screen time before school. But I need reassurance; I need to look up Greenwich Mean Time so I can at least have something to rely on, just one thing to help me get through the day. I am breaking the rules. But I have to, to survive. I find the correct time and immediately a sense of calm floods over me. Finally, something to rely on. I set my watch and two clocks, and in an instant my life is bearable again. Now, to face the breakfast table. The rule is be downstairs by 7.30am. It is immeasurably pleasing me to know it is 7.27am.

Downstairs; 7.28am

"Morning Mum".

"Oh, good morning. But please, sweetheart, remember the rule - downstairs by half seven? It's gone half seven..."

"No, Mum, it's..."

"Please don't argue, just try a bit harder tomorrow..."

Meltdown ensues.



Heather MacKenzie

Speech and Language
Pathologist and Founder of the
SPARK* programme (Self
Regulation Program of
Awareness and
Resilience in Kids)

www.drheathermackenzie.com spark-kids.ca

Some mistakes are pretty minor in the whole realm, like writing your name in the wrong place – you can erase it and start again. Other mistakes have serious consequences, like not doing up your parachute before jumping. It's the context of a mistake coupled with the consequence of it that determines how important it is to tackle it immediately.

Context

If your child has had a long day and is tired, he justifiably won't be too open to correction. If he's had people correcting him all day, he's unlikely to tolerate more.

Consequence

If your child will lose out on some opportunity because of his mistakes, maybe it's worth getting him to correct them. An error may cause him social embarrassment; then it's worth helping him correct it. When a mistake could jeopardize your child's safety (like forgetting to do up his seat belt in the car), then you have no option but to correct him.

If your child's mistake will have no impact on his opportunities, social standing or safety, it might be worth re-evaluating whether you correct him or not. This decision should be made within the context of his day – if he's tired and/or has been corrected all day, ease up.

Mistakes are, however, part of learning and you don't want your child to continue making the same errors. How do you approach correcting him? I've had good success prompting parents to explain: "It's my job to help you learn and part of that is to help you fix mistakes. Everyone makes mistakes because that's how we learn."

Then, using your judgement about context and consequence, decide when to correct your child. If the situation is appropriate, talk to him first. Tell him that you have to help him learn so sometimes you will correct him.

Then ask him how many times he wants you to correct him in the next while – remember, you can negotiate the number.
Ultimately, you want him to be able to notice and fix his own mistakes. You can work with your child to make a checklist of things to look out for. The example below is a checklist for cleaning his room.









THERE'S probably not a single parent reading this who hasn't at some stage had to have an uncomfortable conversation with their child's school. Mainstream settings can struggle to understand our kids and some are lamentably short of decent strategies. The question is, what can we parents do about it?

It's right that we should demand more knowledge and training for ALL schools. In the meantime, here are some tactics that I've found useful when grappling with a thorny education issue.

By Debby Elley, co-editor and mum of 13 year-old twins with autism.



Breathe Deeply

If someone was wielding a stick at your child, you'd dive on them and whack them hard - it's a natural instinct.

But misunderstandings can be handled in a gentler way. If teachers rigidly try to apply the same rules to your child that have worked with the others, you can quietly address this and guide them towards better approaches. Stay positive - point out what WILL work so that your conversation is solutionbased rather than a list of criticisms. Give reasons why certain strategies work better than others. For instance, any 'persuasive' strategy that involves putting pressure on an autistic child is highly likely to become unstuck, because of high anxiety and poor selfregulation.

2

Build A Team

Prepare to battle from the same side. It's very hard for school to feel on your side if they are under attack. If someone was implying you were rubbish at your job, you'd probably get defensive and angry. You'd assume that the accuser was unreasonable and you'd stop listening to them. So, for small but annoying misunderstandings, keeping your language neutral will foster a spirit of co-operation.

So, talk about a 'situation' using the term 'we'. The message is: 'How can we put this situation right, with our joint knowledge of this child?'

If the school isn't responsive to this despite your best efforts, you'll need to switch tactics, see Point 10.

3

Wait for Half-time

Avoid chatting at the classroom door when 30 other children are grabbing coats, locating parents and making a load of noise. Use that one minute to request a meeting or leave a note of times you're available.

4

Champion Your Team

Everyone likes a pat on the back and sometimes it's as helpful to tell teachers what is working well as it is to flag up what's not working. If things are good, email a little thank you note, copying in someone senior and point out why it's working well. This will make staff far more open to listening if ever there is a problem in future. It will also reinforce good practice.





Match Analysis

You're frustrated, the person you want to speak to is not available right now, so you grab the nearest keyboard and write an essay.

And don't get me wrong, I bet that essay is great. But how much progress are you making here?

A long email – however skilled its content – can't help but appear to be a rant. Also, what it can't do is listen. So it can't build trust and a supportive relationship, which is exactly what you need if you're to progress with the school's understanding of your child.

An e-mail attacking a third party is also difficult for a headteacher to respond to without leaping to the staff member's defence.

If a situation has upset you, it's always better to have a face to face talk in a calm setting. You'll get so much more information through body language.

That said, if the problem is delicate, it's sometimes a good idea to send a premeeting outline of the situation and what you're hoping for in terms of solutions. Just don't rely on emails to sort out the entire problem.



Don't Sit on the Subs Bench

You may have someone you trust who is an outreach worker or part of an autism advisory service. These people can be really useful in backing you up and giving you a voice.

By all means get them involved, but whatever you do don't hand over to them entirely. You want to be seen as part of a problem-solving team, not separate from it. What if that key person moves jobs? If they can explain anxiety better than you, then it's over to them at meetings. But be there, chip in, stay active.



Keep Score

Whilst reams of emails don't work, it's helpful to keep a log of phone calls and approaches just in case you get nowhere. If you wish to make a formal complaint to school, do so with a postal letter and ensure you keep a copy and that it has the date on it. Remember to work through the school's internal levels of seniority before you engage in any legal action.



Make a Strategy

I've been to plenty of meetings where a problem is discussed in circles and debated in length, seemingly to help everyone have a deeper understanding of it. The meeting ends, you leave the room, and no one has a clue what happens next.

Be clear from the start that you'd like to leave the meeting with some ideas about what to do next. Once everyone has a clear understanding of the problem, ask the school for options and suggest some of your own. Preferably go into the meeting with some realistic ideas on standby. And if you're not sure of the answers, one option would be to get an outside autism specialist to assess the situation.



Tackle Your Feelings

Often our emotional words are driven by underlying fears that other people can't see. Teaching staff may respond to those words without actually understanding your background fears.

Maybe a small situation has made you feel that this is the thin end of the wedge. Maybe one person misunderstanding your child has led you to believe that no one at their setting really gets autism. Maybe something happened in the past that has traumatised you in similar situations.

Be truthful if you need reassurance or are feeling emotional. This will stop them from assuming that you're overreacting.



Time for Penalties...

Start by using points 1-9. What you're looking for is willingness to listen, openness to suggestions, good communication and quick changes, or at least a timescale for them. If you get defensiveness, rudeness, rigidity, lack of communication or snail-style progress, you need to shift gears.

Start by making sure you haven't misunderstood your child – be willing to look at this from all angles and be open to the idea that they may have misinterpreted a situation.

Know the law and quote it, see right. If you still have no luck, contact the National Autistic Society's Education Rights Service on 0808 800 4102 or IPSEA (see right).



Points of Law

Under the Equality Act 2010 schools are bound to think proactively rather than reactively about giving people with disabilities equal chances. This means they need to use all means possible to remove potential barriers. . The term 'reasonable adiustments' means that the school should operate so that disabled people are not automatically disadvantaged by certain policies, procedures, practice and premises. Policies are the key area where I've experienced staff close to breaking the law. You need to have a good understanding of autism to recognise what is lack of discipline and the type of behaviour caused by stress and anxiety.

Further Information

Geraldine Hills founded the Inclusive Choice Consultancy when her own son was badly discriminated against in his school. Her aim was to make information and advice clearer for other parents

If you're having problems getting your school to listen, you can download Geraldine's book A Parent's Guide to Disability Discrimination and their Child's Education free of charge from www.inclusivechoice.com/books or order a print copy for £5. Other helpful books are also available from the same site.

This site also has many useful links and even template letters to help you resolve your situation.

Inclusive Choice Consultancy offers several short training courses for parents. **Getting the Message Across** will help arm you with great communication skills and **A parent's guide to disability discrimination and their child's education** will mean you're never caught out by lack of knowledge. Go to www.inclusivechoice.com

IPSEA (Independent Parental Special Education Advice) can also help with free legal advice at www.ipsea.org.uk

.

Is your school based in Manchester or Cheshire? AuKids provides awareness training and workshops to raise funds for the magazine.

Autism Through the Looking Glass Reflecting on the pros and cons of medication



Dr Pru Allington-Smith has been a Consultant Child Psychiatrist for those with learning disabilities since 1998. working for Coventry and Warwickshire Partnership NHS Trust. Last November, AuKids attended her workshop on medication at the **Autism West Midlands** conference 'Exploring Autism Interventions'. In this feature, we share some of her responses to the key questions surrounding medication for autism.

Q: What sort of problems associated with autism can medication help

A: One in four of the population will suffer from significant mental illness at some point in their lives, but in people with autism, anxiety disorders, OCD and depression are more common than in the general population. Eighty per cent of the children who I see at CAMHS also have autism. It's not surprising that some of the key aspects of autism, such as social difficulties, can eventually have a big knock-on impact on mental health. Medication can be helpful in some circumstances for these issues, but would rarely be our first port of call.

Q: Can you medicate for difficulties that are part of the autism itself, such as repetitive behaviour?

A: There are no medications that treat autism itself. Most medications that are used reduce anxiety, which is often associated with distress and with behavioural problems in autism.

Q: At what stage would you consider trying medication?

A: Medication is very much the last option. Looking at how the individual communicates is important and for some children, sensory strategies can be very helpful. It is also important to consider whether the physical environment someone is in could be contributing to their problems. In anxiety disorders and depression. talking therapies such as CBT (Cognitive Behavioural Therapy) can help children to retrain unhelpful thoughts. The benefit of these interventions is that unlike many of the medications, they can result in life-long positive changes. Some versions of CBT can be done online which tends to appeal to older youngsters with autism.

The drawback of these is that this sort of training can be impossible for someone with learning difficulties, or who has trouble transferring skills. Psychological therapies usually require 8-10 weekly sessions. Plus, if someone has severe depression, they may not be able to do the therapy.

drink me

There is no way that Alice consulted her paediatrician before taking this

Q: I would be worried about giving medication to my child. At what age is it safe?

A: All medications must be tailored to the individual but it would be highly unusual to consider medication below the age of 6 years and mostly children are much older. The only exception is Melatonin for sleep.

Q: At what stage would you suggest medicating for anxiety?

A: Anxiety disorders can present as generalised anxiety - feeling very anxious most of the time which is very common in autism. Then there are simple phobias and panic attacks for which medication is not recommended. When other behavioural interventions like the ones I've mentioned aren't working, medication can be helpful when there are severe problems – and can be used in conjunction with other therapies. Severe problems might include self injury, severe aggression or anxiety so severe that the individual cannot go out or function in the community.

Q: How do we know when to treat depression?

A: We say that depression turns from being 'down in the dumps' to a clinical diagnosis when feelings of profound sadness present most of the time for at least three weeks. It may be in response to something in particular, or there may be no discernible cause. What we look for is loss of interest in activities, poor concentration and poor sleep. It may be associated with anxiety and irritability. Depression in children with autism isn't always obvious; it can manifest itself as a child being disruptive or self-injuring. Again, unless the depression was severe, we would try other routes before medicating.

Q: Is OCD part of autism or not and can we medicate for it?

A: OCD is a form of anxiety disorder which is associated with repetitive thoughts and behaviours. It's present in 2-3% of the population but is much more common in autism. Autistic rituals can be a sign of OCD and clinicians have a dilemma over whether to diagnose it separately or to put it down to being part of autism. We tend to diagnose it separately when it is experienced as distressing and tiring, and is seriously interfering with daily life.

We've all had that 'I've left the oven on' feeling once or twice, but in OCD this type of checking behaviour is sustained. It can also show itself through intrusive thoughts about having done something wrong, when you haven't, or in having to perform certain rituals before you can do an activity. Again, this is common in autism, but intervention will depend on how disruptive to a person's life that behaviour is. We can medicate for OCD, but again some psychological therapies are also very helpful and would be tried first. Medication rarely treats symptoms on its own.

Q: Who can tell me whether my child needs medication?

A: Your GP can refer you to your local CAMHS (Children and Adolescent Mental Health Services) team. In my CAMHS team, we have mental health nurses, a speech and language therapist, an occupational therapist trained in sensory integration and a

clinical psychologist. It is the job of the team's child psychiatrist to work out whether an illness is physical or mental. Psychiatrists are medical doctors who have then specialised in psychological disorders, so can prescribe medication. They have the training to detect any physical disorders which can be associated with mental health problems. They also have some training in psychological therapies.

Psychological therapies will take you down a nonmedication route first. A Clinical Psychologist is a professional who has a Psychology Degree and further extensive training in Clinical Psychology, working with people who have mental health problems and/or behavioural problems.

Q: What are the drawbacks of medication?

A: Medication can be helpful, but:

- It generally only works while you take it
- Side effects are common
- It may lose its effect after taking it for a while

Q: In your view, should we medicate for autism?

A: For most mental health issues, I would always try behavioural measures first. We need to bear in mind that all medications have side effects and these can end up as problematic as the issue itself, so there are always risks with medication and it isn't a decision to be taken lightly. If other measures haven't worked and a person's quality of life is in jeopardy, then medication can be appropriate. But it will need to be monitored very closely and you must immediately tell your GP if your child is experiencing side effects. This is particularly problematic with non-verbal children, who may not be able to report what they're experiencing.





For extra advice on sleep: AuKids issues 3, 15 and 32 on the archive at www.aukids.co.uk

Sleep
Difficulties and
Autism Spectrum
Disorders: A
Guide for Parents
and Professionals

and Professionals
by Kenneth J.
Aitken, published by Jessica

Aitken, published by Jessica Kingsley Publishing. www.jkp.com



Breaking
Free from
OCD: A CBT
Guide for Young
People and Their
Families by Jo
Derisley, Isobel
Heyman, Sarah

Robinson and Cynthia Turner, published by Jessica Kingsley Publishing. www.jkp.com

A Brief Guide to Medication

For generalised anxiety disorder

Beta blockers were originally used to treat high blood pressure and heart arrhythmias. They block the body's response to anxiety and are designed to keep the heart rate steady. These can be effective for generalised anxiety disorder. Side effects can include low blood pressure, cold hands and feet and a heart rate that is too slow.

Benzodiazepines such as Diazepam and Lorazepam work by affecting the brain's GABA receptors. They lessen brain activity to reduce anxiety and cause sedation. Over time, though, the brain is able to bypass them. This medication only works while you are taking it. Side effects are common and it may lose effect after a while. Drugs like Diazepam and Lorazepam are addictive and become less effective the more you take them. They are best avoided.

For depression, anxiety and OCD

SSRI drugs (selective serotonin reuptake inhibitors), such as Fluoxetine, Sertraline and Citalopram are anti-depressants that also help anxiety. They work by increasing the levels of the chemical Serotonin in the brain (by preventing its reabsorption). They are relatively safe but side effects can include nausea and headache initially. Very rarely, they can make people more agitated. These medications can also be useful in severe depression and in OCD, although in OCD large doses are sometimes required to help. In depression, treatment for at least 18 months is usually advised. For anxiety and OCD, treatment can be longer. Some people experience great difficulty coming off the medication.

Which drug to use will depend on the particular symptoms of the patient, for instance someone who experiences a lot of physical symptoms of anxiety, such as a racing heart, might respond to a beta blocker.

Risperidone, Aripiprazole and the older drug Haloperidol are some examples of antipsychotic drugs which in standard doses are used to treat Schizophrenia and Bipolar disorder. In small doses they can help severe anxiety, but there are many potential side effects.

For ADHD

ADHD is present in about 1 in 5 children with autism. Half of children will grow out of ADHD by their late teens; half still benefit from treatment as adults. Drug treatment is usually recommended with ADHD that has a significant impact on learning and wellbeing. Treatment is usually with either the stimulant medications Methyl Phenidate and Dexamphetamine or the non-stimulant Atomoxetine.

For sleep onset disorders

Sleep issues are very common in children with autism, who often say that their thoughts won't calm down enough for them to settle to sleep. Most children are sleeping well by teenage years and many non-drug interventions given by sleep counsellors can be very helpful.

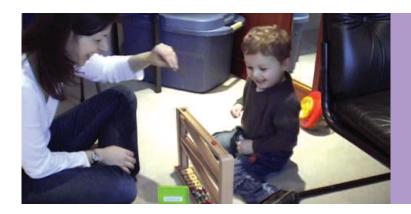
If severe enough, sleep issues can be treated with Melatonin. Melatonin is a hormone produced in the Pineal Gland in the brain. The hormone is regulated through light coming through the eyes and when levels are high, the brain tells us we need to sleep. It may be produced less in children with autism or not be produced at the right time. Although Melatonin is a safe drug, it is only licensed for older adults so you need a specialist to prescribe it. If children go to sleep well but are waking during the night, it is better to use

behaviour interventions.

Medication can be used to treat anxiety

I'M LATE, I'M LATE!

Putting Parents Back in the Driver's Seat



THE co-editors of AuKids magazine met in 2007, when journalist and mum Debby Elley brought her twin boys to see speech and language therapist Tori Houghton. The techniques Tori used with both boys were part of the PACT study, which has this year hit the headlines for its successful results. Here, we discuss our personal experiences of a technique that puts parent and practitioner on equal footing.

By Debby Elley and Tori Houghton

What Is PACT?

Led by Jonathan Green, Professor of Child & Adolescent Psychiatry at the University of Manchester, the Pre-school Autism Communication Trial (PACT) was a three-year social-communication intervention involving 152 children that took place across three research sites in 2006 – Stockport, Newcastle and London. The children, aged 2-5, were randomly assigned two groups – a treatment one and a control group.

The 'treatment' group received fortnightly speech and language therapy sessions for six months, reducing to monthly sessions for a further six months. Their progress was measured using parent questionnaires as well as the standard autism diagnostic test (ADOS - Autism Diagnostic Observation Schedule) at the beginning, after six months and at the end of the trial. The control group completed the assessments, too.

The PACT study was designed to train up parents to become communication experts with their own child.

It was based on the understanding that parents know their child best and speech and language therapists know communication best, so in effect was a pooling of skills.

What Happened in Therapy?

During a session, a parent was videoed for ten minutes playing with their child. The parent and therapist then watched it back together, with the therapist encouraging the parent to look out for positive interactions, enjoyable moments and communication signals.

The basis of the approach was to help parents identify key moments when language and communication was happening and to be able to capitalise on them in future at home.

PACT Results

Results showed that those children who had received the PACT treatment showed less severe autism behaviours according to the ADOS assessment. Children also initiated more communication with their parents. What was most significant (and what made the headlines) was that these changes were sustained in the follow up study six years later. This had been difficult to achieve previously.



TORI'S STORY

I'd worked as a speech and language therapist for about six years before I started working as a research therapist on the PACT trial. Working with autistic kids and their families was not new to me, but the way therapy was delivered - by drawing out answers from parents rather than imposing my view on them - was. This approach, taken from the field of psychiatry, felt very different. At first, it felt like the long way round of solving a problem, but over time, I realised how important it was to allow a parent time to come to their own conclusions and how much more powerful working this way could be.

A parent wrote a card to me, saying 'the treatment has helped me to create a bond with my son that will never be broken.' This was done by asking questions about what was happening in the videos. Initial questions would cascade down to help parents hone in on something more specific. E.g. When did you feel more connected with your child? How did you know he was enjoying that? What exactly was he doing at that point?

This approach didn't just teach parents what to look out for in their child's emerging communication skills. Far more than that, it taught them to zoom in on the positives. Emotionally, that had a farreaching impact.

During video playback, we were able to see things that we hadn't noticed the first time. In one session, we picked up on a word a pre-verbal girl had said which we'd missed during the live play session. It was a chance to revisit these moments and replay them, trying to work out what was happening, what the parent had done to create that opportunity and what the child might be thinking at the time.

We know that autistic kids do give communication signals but because they are weak, they are often missed. Video playback gave the opportunity to see these missed signals and show parents that communication was happening. As a therapist, it was empowering to show parents that it was them bringing out the specific communication opportunities, not the therapist. This helped them become more confident in their own skills.

By focusing on interaction and giving



CLOSE CONNECTION: Debby learned to read Alec's signals



parents the skills to support their child's communication, it also led to parents feeling that they connected with and understood their children better. One dad said to me he went to a meeting at his son's school and he really felt able to talk on behalf of his child; he felt he knew his son better. He recalled that he had sat in meetings prior to PACT letting professionals speak, unsure of what to say.

Another parent wrote a card to me, saying 'the treatment has helped me to create a bond with my son that will never be broken.'

Rather than setting a target on something a child isn't achieving, the targets were set for the parents to increase something they were doing already.

I felt at the time that this was huge, because we were giving parents back their children. Their hard to read youngsters had become readable, simply because their observation skills had been more finely tuned.



My twins weren't actually part of the PACT trial (twins were not eligible). However, since Tori was using the approach at the time we met, we adopted it anyway and I've been able to see the results first hand, ten years on.

I had very limited experience of speech and language therapy at that point. I was expecting a clinical atmosphere and to 'hand over' my children to someone else to work on.

Working with a speech and language therapist to improve my own skills was just what I felt I needed, as I had previously been at a loss over how to play with my twins.

PACT helped me to see my relationship with the twins in slow motion and because of this, I began to learn what ticked their boxes in terms of interaction.

Alec, then three, was not engaging with me very much. He seemed to be extremely shy and we actually learnt later that he was experiencing overload.

When Tori paused the video of me and Alec, I saw immediately that his body language suggested my animated behaviour was too much for him. I couldn't believe how 'in his face' I was, so desperate was I for a reaction! It really was a slapped hand to forehead moment.

After that, I gave him space and didn't set my own agenda. You can see my distance, right, with Alec in the green checked shirt. In later videos, I saw his whole body language change as he positioned himself towards me and invited me to play by handing me his toys. We still do this now!

With Bobby, simply learning to follow his lead and supply simple words was all that was required. To hold back and not impose new ideas on him was at first a strain for me. But I got used to it and it completely changed our interactions.

Sometimes, Bobby would copy me. If it hadn't been videoed, I probably would have missed it, because he wasn't copying immediately but some minutes later after he'd processed it. So those tiny signs taught me not to give up.

Looking back on this, the communication I now have with my boys completely stems from this approach. I am very close with both twins and there is a strong trust which has been the basis of all of our progress ever since.

I think the reason PACT's long-term results are so good is that learning to look for subtle signals just becomes a way of being.

I'm not saying everyone should get a video camera! I do think just being mindful of weak communication signals makes all the difference in interactions with your child.

FURTHER INFORMATION

- The PACT project resulted from a major collaboration between The University of Manchester, University of Newcastle, Institute of Child Health, London, Guys Hospital, London, Institute of Psychiatry, Stockport Primary Care Trust, Lewisham Primary Care Trust, Southwark Primary Care Trust and North Tyneside Primary Care Trust.
- To read more about PACT, see the original research paper in The Lancet and find out more about the PACT-G study being delivered in schools, go to: research.bmh.manchester.ac.uk/pact



Moving Heaven and Earth to Be Inclusive?

Places of worship tend to be a bit like libraries. Because of this, it's often tricky to take your autistic youngster along with you for fear of disturbing everyone or causing a fuss. Inclusion and worship should of course go hand in hand and fortunately a number of understanding places are paving the way in this respect. Here we share some heart-warming experiences. Could these help persuade a place where you worship to be even more inclusive?

We go to a Baptist
church and it is inclusive
without making an effort to be so.
It is relaxed and I've found my boys
to be well accepted, when they were
younger and made a noise or climbed
younger and made a noise or climbed
under everyone's chairs... and even more
under everyone's chairs... and even more
come to church with them. My oldest
now plays the drums in the church
now plays the drums in the church
music group! [He is quite a
talented drummer!]

Menorah Reform Synagogue

Sharston, Manchester

As a small child, I remember sitting upstairs with my mum in the women's section of our Orthodox synagogue. I was very bored, the service was in Hebrew, and if people started chatting then they received some stern looks. I did cope, but then I didn't have autism.

When my twins reached 13, I assumed that their coming of age ceremony, a Bar Mitzvah, would be impossible.

For a start, it involves reading Hebrew from a scroll to an entire congregation. Just to make things extra easy (!) the Hebrew written in the Torah scrolls doesn't have any vowels, either. It is notoriously tricky to read and takes months to master one section.

As fortune would have it, the lady who runs the synagogue's Sunday school also teaches at an autism school during the week. Her

entire focus was on what WAS possible, not what wasn't – and the synagogue backed her 100%.

Bobby learnt some short Hebrew prayers, with the words spelt out in English letters. He also practised reading an English commentary. For Alec, who is non-verbal, prayers were recorded on buttons for him to press. He was also given meaningful jobs, like opening the Ark, the cupboard containing the Torah scrolls. With support, he took the silver decorations from the Torah and handed the silver pointer to the Rabbi, resisting the urge to twiddle everything.

As a sensory-seeker, Alec also found the Torah's silver bells worth a shake or two, but he had his own box of fidget toys on standby! Bobby, meanwhile, having practised for five minutes nightly for some months, read beautifully.

Our teacher, Tanya Brooks, even created prayer books especially for Bobby and Alec, where prayers were bordered by images of Pokemon and Thomas the Tank Engine. This kept them occupied during the sections of the service where they weren't involved. There is also a partition in our synagogue that is open during services – it leads to the library area which has toys and crayoning in it. Autistic kids don't have the monopoly on difficulty sitting still, after all!

On our advice, the Rabbi announced at the beginning of the service that people wishing to congratulate Bobby afterwards should simply 'high five' him to avoid social overload. In a very cool gesture, he had also worked his entire sermon around the theme of Pokemon.

Afterwards, the congregation were full of warmth and support. Knowing that we overcame obstacles to manage this special occasion seems to have inspired others in a way that I hadn't predicted.

Debby Elley

Inspire Church

Levenshulme, Manchester

This is a small United Reform Congregation church, which meets in the cafe of a community centre. Of the 12 or so children who attend, one has cerebral palsy and autism, another has Down Syndrome and two are adopted. We also have an adult with autism who occasionally attends, a Hindu who finds Jesus 'interesting' and a woman with mental health issues.

It's the most inclusive place I've ever worshipped in, but I suspect a lot of church-goers would shudder at the informality that can sometimes spill into chaos!

Students from local special needs school The Grange attend the café at the centre and asked whether they could run an autism awareness event there, and so this is now in the pipeline.

Anne Priest



INSPIRING CREW: Inspire's Nativity play

COVER STARS: Menorah Synagogue was so proud of the inclusive Bar Mitzvah that they featured it on their latest magazine cover.

I take my twins (both diagnosed with autism) to church and they are included in everything. My daughter with autism has even been asked this Sunday to hand out the welcome sheets despite the fact she has huge anxiety and is selective mute! My son is non-verbal and flaps throughout the service but he is so loved and accepted.







New Life Church

Biggin Hill, London

When Leo was around four, we attempted to attend our local church. He screamed and cried as he banged on the glass door leading out of the foyer back into the car park. I tried coaxing him in for maybe half an hour, we ended up heading home, both of us in tears and exhausted.

It seemed so unfair that other people could do things such as go to church, pop to the shops and go to the park without the screaming, tears, fighting and panic which I dealt with every day.

When Leo was eight, my friend convinced me to give church another go. We arrived and in the foyer the crying and trying to run away began. We were there for a few minutes when someone came out to us. "Is it too noisy for him? Shall I show you the quiet way to junior church?"

> A few minutes later as Leo cried, curled against the

> > wall by the fire exit, someone else came up to me. "Can I help at all?"

I asked for my friend who, seeing I was close to tears, sent me and my youngest into junior church and sat on the floor next to Leo for 10 minutes talking calmly and gently to him.



Welcome to worship! Leo Stoner

We finally all made it into junior church where Leo played on his iPad and ate biscuits.

During singing, the door was left ajar, so he could hear the music as he ran around the table again and again. He was included in all the activities and encouraged to join in. So now we go more often.

When I'm struggling to get Leo through the door, people hold it open and welcome us. At no point has anyone made Leo or I feel uncomfortable or unwelcome. Everyone goes out their way to help, support and simply be kind.

At Christmas they opened their grotto an hour early for children with additional needs. As I tried to coax Leo out of the car with the promise of a plug to charge his iPad once we made it inside, someone came out and stood with me, holding an umbrella over me. Then she promised to find him a plug, so he followed her into the building. He stayed by the plug, but at the end he waved at Father Christmas who smiled and waved back.

My friend's child lay down on the floor in the grotto, so Father Christmas lay down next to her so they were on the same level.

Leo didn't visit the grotto but we made it out of the house, to a social event, and that is a huge deal for us. Without the support and welcome given by our church we wouldn't be able to do that.

Naomi Stoner

My hubby is curate at St James Fletchampstead, Coventry. There are several ASD kids and adults in congregation. Ear defenders are available for those who need them and there is 'cafe style seating' at the back with toys etc. for ASD daughter can happily do her own thing at the back with me without it being an issue for anyone.

Rose Hill

younger kids. Combined with a lively modern style of worship, moving around, repetitive movements etc. are not so noticeable. My



COMMUNITY SPIRIT: Mikey at Eastgate Church

Extra Info



guide to making your environment autism-friendly? Email editors@aukids.co.uk in the subject header and we will email you a pdf.



Pastor Jason Hague has an autistic son and writes a beautiful blog on his experiences. He has also produced what strategies you can put in place to help make your place of worship more inclusive:

012/08/20/invisibleautism-families-howthe-church-can-help

Eastgate Church

Ebbsfleet, Gravesend

In my church, there are around 100 children attending regularly and growing numbers have some kind of SEN, often autism. My own son Mikey is 8 and has autism and he is able to attend the children's groups each week because of the inclusive and carefully thought through outlook of the leaders.

He has a 'passport' which anyone leading his age group can see and it has a photo of him, lists all his special interests and all the things he is good at, along with the things he struggles with. This means that he is understood and welcomed each week.

They also use a visual timetable so that my son knows what activity is going to happen next and they have ear defenders for any children who find noise overwhelming.

It's a brilliant place to be.

Kate Mendez



The Last Word

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

Everyone Needs A Little Anarchy in Their Life

BEING a parent of twins with autism, there's one thing that I miss more than anything else: spontaneity. Do you remember, I muse wistfully to Gavin, as we mop up the tsunami that lies in the wake of Bobby's nightly exit from the bathtub, do you remember how we used to say 'Shall we go to the pub tonight?' and it was actually a possibility?

Then, when we needed it least, we ambled to The Smoking Dog in Wiltshire where we lived pre-kids, ate a rustic dinner, spent our ample disposable income on further alcohol, and ambled home again. unanswerable to anyone but the cat, who never missed us much. And yet I still found plenty to moan about. My job, perhaps. The state of the garden. I don't know. I can't remember what I used to worry about before autism. Maybe it was the fact that in a threestorey townhouse, vacuuming the stairs was a bit of a headache.

All parents feel like they've lost that ability to do things on a whim, it's true. Yet parents of kids with autism have this to a greater extreme. We have to reign in our feelings, because making a huge fuss is only going to spark anxiety and meltdowns. For every new excursion, we need photographs, a Social Story, ample planning, army-like preparation. In fact, even when a holiday club offers me respite for the day, I actually have to weigh up whether it's worth the preparation. Getting the favourite lunch food in (alternatives are often unacceptable), packing it, preparing the kids, reminding the kids, writing it on a calendar, showing them images of support workers, briefing the support workers...it makes me tired just thinking about it.

When the twins were younger, I used to plan a lot for them in the holidays.

I suffered a lot from FOH: Fear Of Holidays. The unscheduled time seemed endless. Now that they're older and they don't get up till later (Wahay! How long have I been waiting for that?!) it is less stressful to be at home sometimes, without the timetable and the preparation, even if it does mean watching the same scene from Peppa Pig 58 times on the trot (pun intended).

Organisations are always asking us what we need as parents and I think sometimes it's hard to figure out what it is exactly we need. One thing, though, that I have formally identified that I need, is permission to be a frivolous, spontaneous, giggly kid every so often. This is the reason why, when AuKids plans fundraisers, we aim to bring out that spontaneity in you, too. Farewell the sensible brain that accompanies you to autism conferences and to school meetings. So long Sergeant Strategist, with a battle plan for every change of timetable. Bring out the silly in us. Remind us who we once were before all this responsibility.

If kids with autism need routine to a large extent, then it follows, doesn't it, that we need a good dose of chaos to offset it every so often? We ignore that need at our greater expense and I did so for years because I found I'd rather sleep away my spare time.

But promise me you'll get out there and party every so often. Not those parties where you have to make a good impression and make small talk. The raucous silly get-togethers with friends who knew you before your parental responsibilities took over your life. Ban yourself from talking about autism for an evening. Bring out the silly in you, and I'll be with you in spirit.



Support for me and my family

Our family support services offer a wide range of advice, training and free advice drop-in sessions



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