

# Aukids™

Issue 7  
Spring 2010  
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Positive Parenting for Children with Autism Spectrum Conditions

## INSIDE:



### Holiday Harmony

Your expert guide  
to taking flight  
- the autistic way!



### Power to the Purse!

Our easy guide to  
benefits



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Helping each other  
through diagnosis

**PLUS**



Take up our **SPECIAL OFFER**  
on Rackety's clothing and  
make money for AuKids!





# Letter from the Editors



## Together for autism

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

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



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or visit [www.togethertrust.org.uk](http://www.togethertrust.org.uk)

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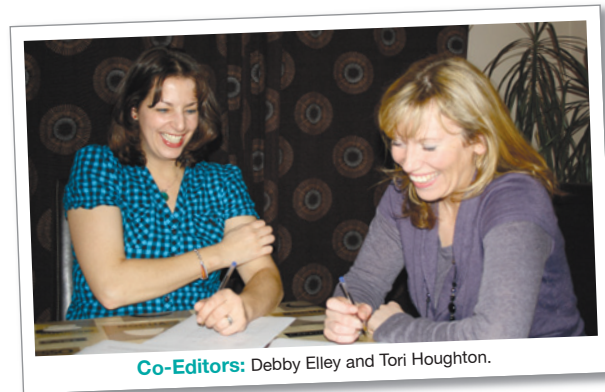


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Co-Editors: Debby Elley and Tori Houghton.

## Hi and welcome to our 7<sup>th</sup> issue!

It's been a hectic couple of months for us at AuKids. So hectic, in fact, that we nearly forgot to write the magazine!

One major challenge has been setting up as a charity. It's something that's important to us because then we can set about getting some serious funding to run AuKids well into the future. Hopefully we'll have some good news to report to you before too long. You'll be the first to hear!

More news - through the generosity of yet another company, Webguild in Gatley, Stockport, we are rebuilding our website and the result will be a bigger, better presence on the Internet later this year. You'll be able to hook up with other members and organisations that are fans of AuKids, too.

Angela and Nigel at Webguild have done us a big favour by using the sort of design that only large corporations can afford at a huge discount that we can manage. A massive thanks to the Joshua Short Foundation who have agreed to foot the reduced website bill.

We're also delighted to announce that Manchester branding and design company Studio North, whose operations director Michael Di Paola approached us, has agreed to provide some sponsorship support. Studio North has already lined up a five-a-side charitable football tournament in aid of AuKids magazine - for details see our news page. Thanks guys! We are still looking for further sponsors to help us with production costs and services, so please continue to pass the word (and the magazine) around!

So you see it's all go, but we didn't quite forget to write the magazine! In fact as usual it was a challenge to fit it all into 12 pages, but we hope you'll enjoy all the advice inside. Keep sending us your news, reviews and photographs!

Thanks for all your support,  
**Tori and Debby**

Our front cover star is Sacha Paddle, see spotlight Page 12.

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### 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.



Subscribe to AuKids online at [www.aukids.co.uk](http://www.aukids.co.uk) or send a £10 cheque with your name and address on the back, payable to AuKids magazine to: AuKids, PO Box 259 Cheadle Cheshire SK8 9BE.



## Five-a-Side Footie Scores AuKids Cash

**A FIVE-A-SIDE football tournament hosted by Manchester brand design consultants Studio North has raised more than £500 for AuKids magazine.**

Six teams of players from North West businesses - plus two referees and dozens of onlookers - braved the drizzle to battle it out at Powerleague Manchester Central for a three-hour football fest. Winners the Boulting Group proudly displayed their miniature match trophies over a well-deserved post-match buffet and beer.

Print companies Paramount and Wrights Printers supplied two teams for the tournament, joined by design and advertising agencies True North and Partners and a team supplied by the hosts, Studio North.

Organiser Michael Di Paola, operations director at Studio North, commented on the matches in amusing detail on the company's blog, recording that his own team were 'Overweight, undertrained, no obvious pattern to our play. Simply dreadful.'

The tournament resulted in a dramatic penalty shoot-out between Paramount Print and the Boulting Group, which resulted in a 1-0 victory for the Boulting Group, who hoisted the carefully crafted ceramic trophy - a mug!

**Many thanks to everyone who took part and gave us such a boost!**



## Donkey Centre Opens in Ireland

UK charity The Elisabeth Svendsen Trust has announced its plans to build a one million pound donkey-riding centre just outside of Belfast, which will provide a free service to hundreds of children in Northern Ireland who have special needs and disabilities.

EST provides unique donkey-riding therapy and has five centres across the UK. It has recently acquired land in Ballypalady near Templepatrick to build a sixth centre, which is planned to open in early 2011.



Donations are required to raise £480,000 towards building and equipping the centre.

For further information, visit [www.elisabethsvendsentrust.org.uk](http://www.elisabethsvendsentrust.org.uk) or speak to the fundraising team at EST's headquarters in Devon by calling 01395 573133.

## Get on Board to Raise Money for NAS

Thomas the Tank Engine fans of all ages and their families can enjoy a fun day out and raise money for the National Autistic Society by taking part in a train walk this year, taking place at locations across the UK. To find out more visit [www.trainwalk.org.uk](http://www.trainwalk.org.uk). At AuKids we're hoping to host our own train walk for the NAS. Check out future updates on our Facebook site.

## Presenter Runs for Autism

Cbeebies presenter Alex Winters is running the 2010 London Marathon to help youngsters with autism. He's raising funds for Caudwell Children's UK Autism Initiative, a project that provides a range of autism treatments and therapies.



Anyone wishing to support Alex should visit [www.virginmoneygiving.com/team/fantasticfour4](http://www.virginmoneygiving.com/team/fantasticfour4)

## Summer Music Fun

Inscape Salford, an autism school run by the Together Trust charity, is hosting a summer music festival produced by children with special needs. Shows will take place at The Lowry theatre, Salford, on Wednesday July 7<sup>th</sup> at 10.30am and 12.45pm. Lowry box office: 0843 208 6000.

## Edinburgh Study Reveals Clues to Autism

A new study at Edinburgh University has discovered a mis-timing of critical phases in the brain's development in people with Fragile X Syndrome. Not all autistic people have Fragile X Syndrome, but it is known that Fragile X Syndrome can cause autism. The study suggests a miscommunication between brain cells, resulting in symptoms experienced by people with Fragile X such as extreme sensitivity to touch and sound and social withdrawal.

By studying the brains of those with and without the condition, the team concluded that the changes in connections occur midway through a baby's development in the womb.

The study suggests that there are critical windows of opportunity where intervention for Fragile X and autism may be most effective.

For more information about Fragile X go to [www.fragilex.org.uk](http://www.fragilex.org.uk)

## Conferences

### The Key to Success

The 4<sup>th</sup> International Conference Communication: The Key to Success will be hosted by Edge Hill University, St Helens Road, Ormskirk, Lancashire on May 21<sup>st</sup> 2010. The conference targets parents and professionals working or living with a young person on the autism spectrum. To register e-mail [carol.wright@edgehill.ac.uk](mailto:carol.wright@edgehill.ac.uk) or call 01685 650 941.

### Autscope

Autscope is hosting its 6<sup>th</sup> Annual European Event in Ammerdown, near Bath on August 10<sup>th</sup>-13<sup>th</sup> this year. Organised by and for autistic people, Autscope focuses on their needs, interests and sensitivities.

The event is described as "a retreat from the demands of mainstream society and an escape to an autistic-friendly space for a few days". Everyone on the spectrum is welcome as well as parents, carers and those working with autistic people. There are also childcare facilities as well as a specialized approach including chill out rooms. The theme of this year's conference is "Autistic Wellbeing" with workshops and leisure activities taking place throughout the three days.

For more details of this exciting and unique event, go to [www.autscope.org](http://www.autscope.org)

### Autism - A Hands On Approach

The 7<sup>th</sup> National Annual Conference Autism - A Hands On Approach, will take place on November 10<sup>th</sup> 2010 at the Pinewood Medical Education Centre, Stepping Hill Hospital, Stockport. For further information or to be put on the mailing list please contact Tanya Farley on 07966 399 709.

## UK's First Legoland® Discovery Centre Opens in Manchester

Merlin Entertainments has opened the UK's first LEGOLAND® Discovery Centre this Easter at The Trafford Centre in Manchester. The indoor attraction, aimed at kids aged between three and 12, offers an interactive and educational experience based on a Lego® theme. There's a 4D cinema, an interactive Lego® ride, a Miniland showing global landmarks and tonnes more, including party rooms.

**The £7.5m Manchester attraction will be the fourth in the world - there are two in Germany and one in Chicago, USA. To book call 0871 222 2662.**

If you have proof of disability for your child, carers get in free, but you can only arrange this over the phone since there is no such option online.



# Ask the Experts

“We’re taking the dreaded plane journey this summer. How can we make the journey easier for our autistic son?”



**Luke Beardon**

Luke is a Senior Lecturer in Autism at The Autism Centre, Sheffield Hallam University

Transition frequently causes stress to people with autism - the disruption of routine, the uncertainty of what is going to happen, the difficulties in understanding what is going to happen and when (all of this in an unfamiliar situation, too) - so experiences such as going on holiday (certainly for the first time) can be a potential trauma.

What is a possible critical 'key' is the provision of a stable, motivating focused activity for the individual - almost as though there is compensation provided to balance out the stresses. For some, the activity will be obvious: favourite films watched on a portable device, for example. One great tip I heard from a parent was to purchase a GPS tracker so the individual could watch the progress of travel - a fantastic idea, and one I wish I could claim as my own! NB Please be absolutely sure to check with the cabin crew before operating any electronic devices on board the plane.

In brief, the following tips may help:

- Break the journey into clear 'chunks' so it becomes a series of 'mini-journeys' rather than a big onerous indecipherable 'black

hole'. Make sure the chunks are available for your child in a manner suited to them - page by page, for example, with photos, or counting down to the finale.

- Have plenty of visual cues to help along the way - advanced planning will really help.
- As far as possible make the journey into a game (with the game as the focus); e.g. match up as many pre-prepared cues with what your child can see.
- Make sure any unstructured times (e.g. waiting for take off) can be filled with as many autism friendly activities as possible.
- Make sure there are plenty of clear, structured opportunities for being autistic - times for your child to engage in being themselves.
- Talk to the airline well in advance - some are amazingly accommodating and will allow you to be last on/first off (or vice versa) if you explain your needs; some may even allow a visit to the cockpit.

“Perhaps explain what's going happen on the plane and then to explain what's happening as it's happening would help (eg. "We're waiting for the plane to move" "The plane is going into the air").”

'Lost Alien', an adult with Asperger's, taken from Wrongplanet.net



**Carol Honeini**

Carol is a tutor who works with autistic pupils in the Royal College Manchester at the Seashell Trust.

Begin with a countdown to the holiday date (using photos where possible). Try to gather pictures of the airport, the type of plane, a typical dinner on board, how the toilets might look, the TV consoles on the back of seats etc - anything to prepare him for what to expect.

Some airports including Manchester also have special guides to travelling with an autistic person so do get in touch to see what help they can provide.

You could also gather photos of activities that are going to be available to him on the holiday, the people he is going with and maybe pictures of the sort of food which might be available to him.

Also, if your child is using photos or symbols, let him know that all his usual items (where possible) can be taken with him and show him that he can easily find food and drink that he has at home. Let him pack his own bag and try and make the journey seem more home friendly rather than a new and different experience.

It is also useful to have a countdown to the return journey and coming home.



**Dr Paul Holland**  
PhD C.Psychol. AFBPsS

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

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

Firstly, it is important to realise that many people experience anxiety in relation to flying. As with any new experience for which there is warning and time for preparation, it is much better to address the issue/s well in advance. A multi-faceted approach in this instance would be best:

- Many airlines operate programmes whereby children with special needs can visit airports and even board aircraft. This provides children with an understanding of what airports are like and what is expected of passengers in-flight.

In your case, your son could be exposed to the crowds, noises, smells and everything associated with airports and flying. Often stress and anxiety, especially in the case of autism, is triggered by the unknown. Exposure reduces this likelihood.

- Visit the airport that you will be departing from

with your son. Try to obtain (via the airport) pictures of the places and things that you will be exposed to when checking in. This way you can familiarise your son to the different steps that you will be required to take.

- After your visit, create a Social Story® about airports, flying and holidays, using the photos and knowledge that you obtained. You should keep the story relatively generic and non-specific to avoid change-related stress. Read the story two to three times a day at least two weeks before your holiday.
- When going on holiday board the aircraft early so that your son can adjust to the environment and have time to associate this experience with his Social Story®. Be sure to have the Social Story® with you.
- Take favourite activities for your son to occupy his time while in the air. Also take foods that your son likes to eat.
- Always reinforce appropriate behaviour and in this instance as regularly and highly as possible. This will reassure your son that everything is OK.
- Be calm. Children pick up on the emotions and reactions of others. If you are stressed, he is likely to become stressed.
- Just remember prevention is better than cure. You can never prepare too much nor too early. Follow the steps provided and most importantly enjoy your holiday!

Bobby's mum Debby Elley (our co-editor) says that she bought sound muffler headphones for her son Bobby, shown here on take-off:

*"The headphones are great for the times when Bobby thinks he might be overwhelmed by strange or sudden loud noises. I've found that even if he doesn't wear them, knowing he has them to hand makes him a lot calmer,"*

she says.



**MANCHESTER AIRPORT** has a leaflet to help people with ASC to negotiate air travel. Download the leaflet at [www.manchesterairport.co.uk](http://www.manchesterairport.co.uk) The free guide, called *Airport Awareness*, explains in pictures what to expect on your journey through Manchester Airport, starting from arriving and checking-in to going through security and returning home.



**Chris Hoyle**

Specialist Speech and Language Therapist at Inscape House School, Cheadle, Cheshire.

The key to any successful holiday is planning and preparation and this is even more important when going abroad with a child with autism. Airports are very busy, noisy places with lots of set procedures to go through - make sure your child understands this.

Depending on the level of understanding your child has, you could use symbols to create a TEACCH\* schedule - remember to include a picture of your destination on the schedule and information about how you get there. If your child is able to read, take a note pad and pen and have a written schedule so that your son can cross off each step of progression towards the plane and then the final destination.

If your son is motivated by comics or sweets you could include a trip to one of the shops to buy a reward once you are through passport control. Remember, the more your son understands about the trip the less anxious he will be.

Waiting for a plane can also be a very tedious

experience so make sure that you pack plenty of things to entertain your son with in the departure lounge, DVDs, MP3 Players, games consoles etc. You can use visually aided narratives (VAN) to prepare children for holidays abroad. These are written at a level to suit the child and take the child through the exact sequence of events that they are going to experience.

You can include vital information such as plane times, but remember to add in scope for delays - so if possible laminate the pages and take a whiteboard pen so you can add in information.

Remember that your son needs to know how long he is going to be away from home for - and again this needs to be done at a level to suit your child.

You could use a TEACCH schedule either showing seven pictures of the same apartment followed by one of your home - and each day the child can remove one picture of the apartment so they can see the progression of time each day, or you could write this down so your child can cross off each day as it passes, or take a small calendar.

Don't forget that you need to think about what you will do on the holiday - prepare as much information as you can before you go, and don't forget to prepare for the return journey too!

Hope it goes well, have a great time.

\*TEACCH - the Treatment and Education of Autistic and related Communication-handicapped CHildren. For more details, see [www.teacch.com](http://www.teacch.com)

*"Whilst I love travelling (and living in Oz, the only way you can travel to other places is by plane), I can find airports pretty stressful places especially when they are crowded and you have to go through all the security checks and people around you are grumpy. It can bring on the sensory overload.*

*"I find departing first thing in the morning is best as the crowds at the airport are minimal and it makes the whole process much less likely to overload me."*

Brennan,  
an adult with Asperger's.



Do you have a question for Ask the Panel? E-mail us at [aukidsmag@googlemail.com](mailto:aukidsmag@googlemail.com)







## From Rags to Rackety's

By Debby Elley

MY son Alec has a common autistic trait - he loves twiddling. Sticks, brushes, spoons, wands, potato mashers, fish slices, rubber dinosaurs...the list's as long as it is surreal.

His quiet repetitive behaviour was acceptable in public until one day he had a profound thought. *Why search for something to twiddle when there's a perfectly handy item permanently attached to you? Oh dear. Boys will be boys.*

Then we discovered Rackety's, which makes popper vests and pyjamas in pretty much any size you like. They're just like the usual ones, but with poppers underneath. Inappropriate twiddling is now a thing of the past. In fact, if Alec was ever confronted with life without his trusty popper vests, he'd probably have forgotten what to do with his winkle by now. Which is just as well if you ask me.

Specialist clothing such as this was somewhat hard to come by before Annabel McMahon set up Rackety's, a Staffordshire-based clothing company specialising in children's wear for kids with disabilities.

The brains behind Rackety's hasn't always been making clothes for the disability market, though. Annabel had spent 20 years in mainstream fashion, designing children's accessories for the likes of High Street names including Marks and Spencer, Mothercare, the Disney Store and BHS. Day after day was

Rackety's owner Annabel McMahon gets to work on her designs.

spent poring over drawings for character merchandise and dressing-up gear.

"Wings, wands, tutus - you name it," she says. "We'd spend hours doing a £9.99 fairy dress - every year trying to design a better one. More pink! More sparkle! An immense amount of work went into these things.

"Then I looked at what was available for kids with disabilities and I suddenly realised that there was nothing.

"I hated working for my last company. I was driving back one night thinking: 'I've got to do something different.' I cannot remember a Eureka! moment but I started thinking that maybe this area hadn't had a lot of input.

"Looking on the Internet, I realised there was next to nothing and what was there was hideous. They'd just taken the adults' stuff and shrunk them down.

"It was such a contrast with what I was doing. I researched it a bit further and I went down to my local special school. I'd done some design work and I went in rather shyly saying 'I'm thinking of doing this - what do you think?' and they kind of mugged me! They said: 'Come in - sit down - don't move! We are absolutely desperate for *this*, and can you make *that*?...' When I looked at what was needed it really wasn't that difficult, it's just that hardly anyone was doing it."

Annabel started up Rackety's from her son's back bedroom in Leek. Launched in 2004, the clothing store has since become the place to go for the special sorts of clothing problems that are tricky to solve.

"We understand that everyone gets their main stuff from the High Street. But there are certain areas where you get completely stuck because you need a specific thing - we fill those gaps with High Street quality, beautifully-designed specialist clothing," says Annabel.

Parents of children with autism represent Rackety's second largest client group.

"One of the things we do is provide products that stop kids putting their hands in their nappies. This seems to be an absolutely huge area with autism, where there's a massive need. We do vests and pyjamas with poppers as well as polo shirts for school."

As well as keeping active kids warm, the vests prevent underwear from being exposed, so no one need ever know if your child is in nappies over the 'usual' age. As even the most stoic of

**"It's not just a pair of pyjamas. It's the difference between the whole family going to sleep at night or not."**

special needs parents will tell you, it isn't especially welcome to get other kids indelicately pointing out your child's development delay at soft play centres.

If it's embarrassment that's stopped you from solving a particular kind of problem, you needn't worry. Annabel has heard it all before.

"I'll get a phonecall and I can almost tell before they start speaking why they're calling. They're embarrassed to say that the problem is that their child is taking their nappy and smearing it all round the room."

Annabel says she can actually hear the relief in a customer's voice when she tells them that she receives identical phone calls on a daily basis. "They're quite isolated. It's perhaps never occurred to them that it's actually very common."

The testimonies on Rackety's website are proof that the company has made an enormous difference to families' lives. "It's life-changing - it's not just a pair of pyjamas. It's the difference between the whole family going to sleep at night or not," says Annabel.

Rackety's handy mission statement sums it up

**- Get Dressed, Not Stressed!**



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To show our support for AuKids, Rackety's will also send £1 to AuKids for every order received using the AUK01 code.

Offer available from 25.04.10 to 25.06.10. May not be used in conjunction with any other Rackety's offer.



Look up Rackety's at [www.racketys.co.uk](http://www.racketys.co.uk), call 01538 381 430 or e-mail [info@racketys.com](mailto:info@racketys.com)

## Disability Living Allowance



Disability Living Allowance is issued by the Department for Work and Pensions and is a weekly allowance that you may be entitled to if you look after a child with a physical or a mental disability, including autism.

It's not means tested, so it doesn't matter what you earn and you don't necessarily have to have a diagnosis, but it does help! There are two parts to the DLA, a care component and a mobility component. To receive the care component, your child has to take longer performing daily tasks than they would do if they didn't have a disability. The highest rate is currently £70.35 a week, the middle rate is £47.10 and the lowest rate is £18.65, so it's worth applying for.

Even if your child walks fine, an autistic person who has no sense of danger or who doesn't tend to move purposefully may also be eligible for the lower rate of the mobility component, which means an extra £18.65 a week (lower rate).

There are excellent guidelines on the Government's website and you can even apply online. Look up [www.direct.gov.uk/en/disabledpeople](http://www.direct.gov.uk/en/disabledpeople) or call the Benefit Enquiry Line freephone on 0800 88 22 00 who can send you a claim pack and even arrange for someone to help you fill out the form.

# The Benefit... or the Doubt?

Don't let being uncertain about entitlements deprive you of some essential help and support. Get clued up and you could reap the rewards - which means better support for you and your family. Here's our rough guide to the essential benefits you need to know about.



## Carer's Allowance

If you get the care component of the Disability Living Allowance at either the middle or higher rate for your child, then there's a chance you'll be eligible for Carer's Allowance, too.

This IS means tested - you are eligible if you earn no more than £95 a week. If you earn more than that, look into it further at [www.direct.gov.uk](http://www.direct.gov.uk) Carer's Allowance is £53.10 a week but the amount can be affected by other benefits. To be eligible you must look after the child for 35 hours a week or more, so anyone who lives with their child won't have difficulty on that score. For a form contact the Carer's Allowance Unit on 0845 6084321. For advice on how to fill it in, contact the Benefit Enquiry Line on the number we mentioned earlier.

## The Blue Badge Scheme

It's often thought that you can only qualify for a Blue Badge, which allows you to park in a disabled space, if you have a physical disability. Yet it can be argued that autism, being a neurological condition, is a physical disability! Certain traits that some autistic children have, such as no sense of danger and dangerous behaviour such as running away, can be seen as grounds for an application, although authorities vary on how they interpret the Blue Badge guidelines.



The National Autistic Society publishes a superb information sheet titled **The Blue Badge Scheme** giving advice to parents of autistic children wishing to apply. Look up [www.nas.org.uk](http://www.nas.org.uk) and put 'blue badge' in the search criteria. You can also call the NAS's autism helpline on 0845 070 4004 or e-mail [autismhelpline@nas.org.uk](mailto:autismhelpline@nas.org.uk) to find out more.

## Working Tax Credit

If you receive DLA for your child, you will be eligible for an extra component of Working Tax Credit or Child Tax Credit. For more information, look up this superb site at [www.disabilityalliance.org](http://www.disabilityalliance.org)



## Self Directed Support: Direct Payments/Individual Budgets



Self directed support is a way of giving you control over the help you get for your child by giving you the cash to meet their needs. Direct Payments are an example of this. We've met loads of parents who are too nervous of what it involves to get them. And yet they could make a big difference to you. Direct Payments can be used to help with the cost of respite care, support in the home or a personal assistant to support your child when you're out and about with the family.

The NAS publish a super, free guide titled **Direct Payments - A brief guide for parents and carers of children with autism spectrum disorders**. To get your copy look up [www.nas.org.uk](http://www.nas.org.uk) and search 'direct payments' or call the NAS Publications dept on 0845 458 9911.

Although many local authorities use direct payments for children, some of them are starting to trial Individual Budgets (IBs) for children. This is an overall budget for a range of services, not just from social care. The money can be spent on services, equipment or people to support you. Neither Direct Payments or IBs affect any other benefits. Again, the best route to take is through Social Services who will advise you further. If your child is young, ask your health visitor to refer you to them.



## Free Home Insulation

British Gas has a free home insulation scheme for its customers. If you're in receipt of Disability Living Allowance for your child, and your home is no larger than an average four-bedroom detached, you can qualify for free wall and loft insulation. If you have loft insulation already, British Gas can even top it up for you for free!

This'll save you tonnes on heating bills and make your home more energy-efficient, stopping heat from escaping. If you aren't eligible, but you know someone who could be, you can pass the benefit on to them, even if they aren't a British Gas customer. Good eh? Call 0800 068 0032 for a free survey.

## Other Benefits

**Nappies** Did you know that if your child is four years old with learning disabilities, you may be entitled to free nappies from your Primary Care Trust? Your health visitor will be able to request them. Most areas also have a continence nurse who can help with this.



## Leisure Key Card

Many local councils will issue recipients of Disability Living Allowance with a leisure key, enabling them to access a range of discounted leisure services. Contact your local leisure centre to enquire.

## Disabled Toilet Key

RADAR (Royal Association for Disability and Rehabilitation) runs a National Key Scheme (NKS) to give you access to locked disabled toilets around the country. The easiest way to buy a RADAR key (at £3.50) is to go to [www.radar.org.uk](http://www.radar.org.uk) and click on the RADAR shop. Here you can also buy a guide to the 7,000 UK toilets that operate using the scheme. If you haven't got access to the Internet, call RADAR on 020 7250 3222.



## Cinema Pass

If you are in receipt of the DLA, you can apply for a Cinema Exhibitors' Association Card. For a one-off payment of £5.50, this gives carers free entry to movies when accompanying their child. Great for those times when you're not sure if they'll hack the full film or not! To apply look up [www.ceacard.co.uk](http://www.ceacard.co.uk) or call 0845 123 1292.







## Keeping it Together

**H**aving an autistic child affects every aspect of your life. Alarmingly, the impact on relationships seems to be particularly costly. Divorce rates for couples that have a child with autism have been quoted as far higher than average. For too many marriages, the stress is taking its toll. So how do you get back to being - well, just you?

By Debby Elley

Even the most delightful autistic child can bring about extra pressures and limitations on your lifestyle. Focusing on a child with special needs often comes at the expense of a spouse. There's the extra stress of difficult behaviour on top of different parenting styles, different coping methods and even financial difficulties caused by one parent giving up work. In some cases, parents even feel guilty at having 'caused' their child's autism through their own genetics.

But Dr Laura Marshak, author of *Married with Special Needs Children* (co-authored with Fran Prezant), says that high divorce statistics are unhelpful. "It scares many parents. I don't think it's helpful for parents to assume they must become one of those statistics," she says.

"One of the first things couples can do is to make a decision to protect their marriage; they must understand that they are entitled to a decent marriage, no matter how many needs their children have.

"One of the steps involved with this is deciding that their relationship as a couple extends beyond parenting and that they need to devote at least a little bit of time to it."

**“(Couples) must understand that they are entitled to a decent marriage, no matter how many needs their children have.”**

Paula Perryman, a senior helpline advisor for the National Autistic Society, agrees that lack of time is a major problem and suggests that respite could be the answer.

"We would always advise parents to get an assessment from Social Services to have a look at the family's needs - sometimes that can be the gateway to getting more help," she says.

A strong marriage means a happy family, according to Dr Marshak: "I think it's helpful for couples to understand that protecting their marriage is actually good for their children," she says. "Often parents of kids with disabilities feel that they will be taking vital time away from their children."

In fact, the opposite is true. According to a report by the charity One Plus One\*, children with disabilities who grow up with parents who have a poor marital relationship show evidence of poorer physical health, psychological maladjustment and behavioural problems.

Research points to strong positive links between family cohesion, consistent parenting and healthy behavioural and psychological adjustment.

James Harper from Beacon Counselling, based in Stockport, agrees that giving time to each other is important, but stresses the importance of quality communication.

"Perhaps the single most important thing to remember is maintaining good communication, which whilst a simple statement is not easy to carry out," he advises.

"When there is little or no time left for just being a couple, the worries, concerns, and frustrations can become magnified, and the little

### Ten Ways to Build Bridges

- 1 Focus on your partner's good points as a parent - and let them know!
- 2 Try to share concerns and solutions rather than attribute blame.
- 3 Share a positive or funny story about your child every day.
- 4 Try to find ways of giving each other a break, if only a small one.
- 5 Play to your partner's strengths - you may be good at reading up, they may be better at rough and tumble play. Neither of you can do everything.
- 6 Understand that people show anxiety in different ways - anger can be a way of expressing guilt or worry, so don't be too hasty to lose your temper with an angry partner.
- 7 You may feel too tired to go out - go out anyway. Practise being the old 'you'.
- 8 Try to talk about things other than the children - music, movies, TV, whatever makes you feel human!
- 9 When your partner is having fun with your child, don't always leave them to it, take time to be a bystander and enjoy the spectacle.
- 10 Try not to have a discussion when you're at your most angry. Cool down first and think of what you want to achieve.





irritations that are normal in any close relationship can fester and boil into problems.

"It's really important to keep the lines of communication open. You can do this by being open, honest, and respectful, and by drawing attention to areas that may be difficult to talk about.

"The other half of good communication is listening. By giving each other the time to talk and listening in a respectful way, it helps them to feel heard, valued and supported.

"This doesn't mean that you agree on everything together - that's not possible - but if you are both prepared to work at agreement and compromise and on solving problems together, then it will help enormously in overcoming challenges together."

He adds that coping effectively with disagreement is also key. "A large part of the way counselling works is to promote a relationship where communication is open, honest, respectful - even while focusing on difficult subjects that we each avoid.

"This can help to prevent problems arising and also enable both partners to gain support and encouragement from each other."

One mother stresses the importance of working through arguments knowing that you've got the same goal: "Although my husband and I disagree on the manner in which we parent our children, we are still doing it together and our relationship is stronger because of it. If we can get through a total out-of-control meltdown together, we can make it through anything!"

There is a time, James Harper concedes, where counselling is the best route, and couples needn't wait until they are on the point of break-up to ask for

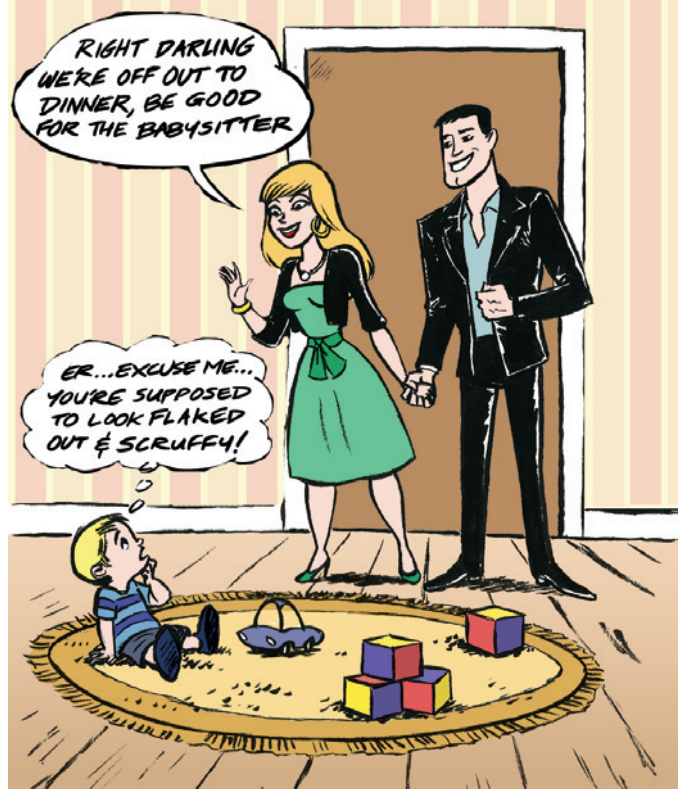
help. "If it gets to the point that you feel stuck, are going round in circles, or are arguing all the time, then it may be appropriate to bring in some extra support," he says.

This needn't be a case of booking weekly appointments and finding babysitters. Certain counselling organisations such as Relate now offer appointments to couples over the telephone, where they can be conducted in the manner of a conference call.

According to the National Autistic Society, one of the most difficult problems couples face is when one member of the family does not accept the diagnosis of autism. "If one parent won't follow the behavioural strategies you should do for managing a child with autism, and the other feels that they are 'undoing' all the good work - that can lead to quite a lot of conflict," says Paula Perryman.

**“ When there is little or no time left for just being a couple, the worries, concerns, and frustrations can become magnified. ”**

In these cases, the NAS Helpline offers to discuss issues over the telephone and then to post out literature to couples. "A parent can show the leaflets to their partner, so it's there in black and white and they can see that research has backed up how certain strategies have worked. We also encourage people to go to support groups or seminars related to autism so that they can hear tips directly from professionals," says Ms Perryman.



**Good parents make time for each other as well as their kids.**

When one partner is in denial, says psychiatrist Dr Paula Salmons, the best way of operating is to find common ground. "One of you may not believe this is autism, but you can both agree on the behaviours that you're seeing that cause you concern.

"If you say to someone 'look, it doesn't matter what we call this, what matters is that we find solutions,' it can cause less confrontation than forcing them to accept a diagnosis when they're not ready. You're side-stepping the actual word for it, but in the short-term that's fine, you can still move ahead as long as you both agree that help needs to be found."

Finally, quoting a parent of a child with Fragile X Syndrome,

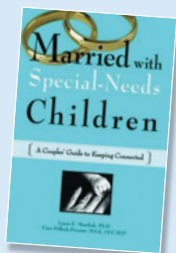
Dr Marshak gives some valuable guidance: "The advice I give to couples who sail into a storm and are fighting is this: don't hack at your boat in a storm. If you are in the middle of a crisis, don't take the very support you have and start whacking at it, because that is dumb. You should love, nurture and care for the other person or you are not going to make it through the storm."

*With many thanks to the American website [www.disaboom.com](http://www.disaboom.com) for giving us permission to reproduce extracts from their interview with author Dr Laura Marshak.*

*\*Taken from the report **Growing Together or Drifting Apart?** written by Fiona Glenn and published in 2007 by One Plus One.*

## Further Information

- *Married with Special Needs Children - A Couples' Guide to Keeping Connected* by Dr Laura Marshak and Fran Prezant is published by Woodbine House and available from [www.amazon.co.uk](http://www.amazon.co.uk) at £17.84. ISBN: 9781890627102



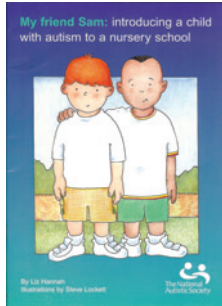
- Beacon Counselling is a registered charity in the Stockport area providing trained volunteer counsellors. Payment is via donations. Contact 0161 440 0055 for an appointment or email [office@beacon-counselling.org.uk](mailto:office@beacon-counselling.org.uk)
- To book a telephone counselling appointment with Relate from anywhere in the UK, contact

0300 100 1234 or look up [www.relate.org.uk](http://www.relate.org.uk) for online counselling.

- The National Autistic Society's Autism Helpline is a confidential information and advice service for people with an autism spectrum condition and their families. The helpline may also be able to find you a local counsellor with experience in autism spectrum disorders. Call 0845 070 4004, open Monday to Friday 10am-4pm or email: [autismhelpline@nas.org.uk](mailto:autismhelpline@nas.org.uk)
- Check that a counsellor is accredited by the BACP. Search [www.bacp.co.uk](http://www.bacp.co.uk) to find an accredited counsellor in your area.
- The NAS also runs a Parent to Parent confidential telephone listening service, provided by parent volunteers. You can call free from a landline at any time and leave a message (you may be charged for calls from a mobile). A parent volunteer will then phone you back as soon as possible. Volunteers can call at a time which suits you. Call: 0800 952 0520.

- Remember that you can change therapists if you're not comfortable with them.
- For families who don't meet the Social Services criteria for paid respite, there are voluntary organisations and charities that can provide extra support. Try the Shared Care Network on 0117 541 5361, Crossroads on 0845 450 8350 or Homestart on 0800 068 63 68.
- The Respite Association provides funding for respite. Call 01406 701 944 for more information or look up [www.respiteassociation.org](http://www.respiteassociation.org)
- For support groups, respite services and training, look up [www.autismdirectory.org.uk](http://www.autismdirectory.org.uk)
- Contact A Family is a national charity providing advice, information and support to the parents of all disabled children. Its free helpline is 0808 808 3556. Look up [www.cafamily.org.uk](http://www.cafamily.org.uk) for further details.

# Reviews



## BOOK

### **My Friend Sam: introducing a child with autism to a nursery school**

By Liz Hannah

Illustrated by Steve Lockett

2007 Published by the National Autistic Society

£7.99 available from the NAS website at [www.nas.org.uk](http://www.nas.org.uk)

ISBN 9781905722228 Code NAS 692

My friend Sam is a book created to introduce a child with autism to nursery or young children in a school setting. The book introduces young children to the differences they may see in an autistic child's behaviour in the classroom in a sensitive and informative way. It is written from the point of view of Sam's, the autistic child's, best friend which helps young children relate to the characters better than if it were from an adult's perspective.

The book addresses early on that everyone who knows Sam "soon learns that he is different". The story then goes on to explain the reasons for these differences in a child-friendly way with bright, eye-catching pictures to illustrate.

The story looks at different aspects of an autistic child's needs and behaviours, including things they may need in the classroom like pictures to help them to ask for things and issues that other children may need to be understanding

about - like Sam not liking loud noises or finding it hard to understand sharing.

The book has a good balance of celebrating the exceptional things an autistic child like Sam can achieve as well as explaining the difficulties they may have in their day to day school life that the children can help with.

The text is effective for use in circle times where the children can then ask free questions about the content of the story.

Overall, the book is a useful tool for class teachers to introduce a child with autism into a nursery or infant setting and to refer back to in circle times to help young children understand the needs, exceptional talents and differences of an autistic child.

A useful resource for teachers.

**Emma Jarrod**

Year 1 teacher at Outwood Primary School, Stockport, Cheshire.

## BOOK

### **The Speed of Dark**

By Elizabeth Moon

2002 Published by Orbit

£7.99 ISBN 9781841491417



This science-fiction story, written by a parent of an autistic teenager, is set in a future where autism in young children has been cured. Yet there remains a group of adults too old for the treatment. One of them, Lou, works for a specialist department in a pharmaceutical company. It consists entirely of high-functioning adults with autism,

whose unique ways of viewing the world offer the company an ability to work out patterns that are beyond the ability of computer technology.

In return, the work environment has been adapted to suit their needs, with a gym for trampolining and their own choice of music.

Lou's ordered life is put in turmoil by the arrival of a new manager, whose mission is to persuade his employees to opt for a new treatment that reverses the effects of autism in adults.

Lou is faced with a terrible choice - to become 'normal' and make the best of his social relationships would mean relinquishing the special gifts that give him some unique and sublime experiences.

As his manager turns up the pressure, Lou's decision becomes more pressing. Would a future without autism be that good after all? Sci-fi blends with social commentary to form a fascinating tale.

**Tori Houghton**

## DOCUMENTARY

### **Autism Reality**

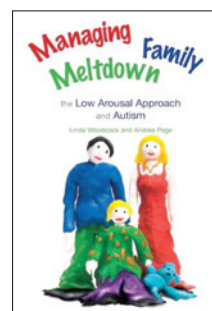
<http://www.youtube.com/watch?v=jLOCYubVc7g>



This 15 minute short documentary by Alex Plank - a young adult with Asperger Syndrome - gives a fresh and real outlook on autism. As well as clips of people's views on autism, reflecting on what it is and what causes it, Alex and his family also relate their experience of Alex's condition. There's also some narration from internationally-renowned speaker Dr Temple Grandin, who has Asperger's, about what it means to have autism.

Alex questions the terms low/high functioning and reminds us how difficult and tiring it can be for him to 'act normal' even with people who know him well. He sums up well how the neuro-typical world can help people with autism, just by understanding that autism "is not a bad or a good thing - it's just a difference and once society starts seeing it that way we're going to be in a better place".

**Tori Houghton**



## BOOK

### **Managing Family Meltdown: The Low Arousal Approach and Autism**

By Linda Woodcock and Andrea Page

2009 Published by Jessica Kingsley

£12.99 ISBN 9781849050098

Challenging behaviour can be one of the most difficult aspects of autism that parents have to deal with. One of the authors of this book, Linda Woodcock, knows this all too well. Her son Christopher, now 21, has autism and severe learning difficulties. This book helps to improve our understanding of why behaviours may occur by describing them as "distressed behaviours" and seeing them as symptoms of discomfort, pain or anxiety. It also empowers parents by helping them to focus on their own responses to these behaviours and change the factors that affect a child's behaviour and are within their own control.

*The Low Arousal Approach* means understanding that distressed behaviour is caused by the 'flight or fight' reaction to extreme arousal - and that this can be managed by reducing demands and being aware of our own non-verbal reactions.

There are activities and questionnaires to help you reflect on your own responses to behaviour as well as a chapter on siblings and relationships and some great analogies along the way that help readers to view 'distressed behaviours' from a different angle.

Overall, this book should help parents take better control of difficult situations through greater understanding and useful strategies.

**Tori Houghton**



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





## Don't Let Language Let You Down

By Tori Houghton, specialist speech and language therapist in autism.

Consider this well known drawing on the right. On first glance, what can you see? The old lady? The young lady? Once pointed out, most people will be able to see both and change their perspective from one to the other.

As neuro-typicals, i.e. people without autism, we have the flexibility to see things beyond the obvious, to consider the non-literal meaning behind pictures we see and the language that we use.

If we were to consider the language around the labels we use to describe children with autism, they are generally considered to be negative words, e.g. "John is aloof, obsessional and rigid." By using our ability to be flexible and changing the adjectives we can make these labels sound more positive instead. Perception is everything, and once you start changing the words you use to describe people, you change perceptions of them, too.

Why don't we re-label John as 'independent, passionate and accurate'? Instead of Caitlin being 'different' let's describe her as 'unique', Connor as 'determined' rather than 'oppositional' and we'll call Sarah 'effervescent' rather than 'volatile'.

The meanings haven't really changed, we're just now focusing on them as positive, useful and favourable descriptions instead.

Some days, as with the picture, you may only be able to see the old lady, other days you can see them both. But sometimes it is helpful to take time to really look at the young lady and focus on these positive traits instead. In the case of your own child, focusing on the positive will help others to champion their strengths and see them in the same loving way that you do.



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For more information about any of these services, please contact Amy Stanion, Services Coordinator, Springside House, 1 Brownsville Road, Heaton Moor, Stockport SK4 4PE. Telephone: 0161 443 4060 Email: amystanion@cygnethealth.co.uk

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# Readers' Page



**Aemee Drew**  
aged 12

## Celebrity Spotlight



**Sacha Paddle**  
aged 8

**Diagnosis:** Autism and severe learning difficulties.

**School:** Russet School in Cheshire, a school for children with special needs and learning disabilities.

**Best habits:** Eating and swimming.

**Worst habits:** Eating inedible objects.

**I love:** Eating, being outside - anywhere! Soft play, sensory rooms, the park, trampolining, holidays and having fun. I also love rough and tumble play!

**I hate:** People not understanding me. Waiting around!

**Lyric that most describes me:** *Yellow*, Coldplay. "Look at the stars, look how they shine for you - and all the things you do..."

**If I were Prime Minister:** I would buy a big house for everyone to have fun together.



**Diagnosis:** Autism and learning difficulties.

**My Family:** Mummy and Daddy.

**School:** Rosebank School, Barnton.

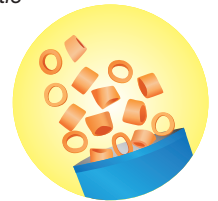
**I love:** Playing with Granny's dog, dolly, Hula Hoops, swimming, Cbeebies, riding my trike, trampolining and custard.

**I hate:** Queuing and waiting and any hair or fluff on dolly's face.

**Song that best describes me:** *Dream a Little Dream* by The Mamas & The Papas.

**If I were Prime Minister:** I would ensure there were out of school clubs for children with autism and free Hula Hoops for everyone.

**Ambition:** To be able to talk - and to own a custard factory.



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

P.S.

The rather swanky website Families Connected is the brainchild of mum and businesswoman Carol McKiernan, whose 11 year-old autistic son inspired her to help others find good support. The forum can be reached at [www.families-connected.org.uk](http://www.families-connected.org.uk)

Yet another inspired mum of a disabled child set up the brand new website at [www.mumsmeetup.com](http://www.mumsmeetup.com) to help you find an easy way to hook up with other parents in similar circumstances in your own area.

Do you find that after a while, the rubber tentacles on sensory toys can stick together, spoiling its tactile feel? Tip from The Novelty Warehouse - give it a quick rinse (a damp cloth is better for light-up ones), dry off and sprinkle some talc on it. Good as new!

Have you ever longed for an Ebay-style site that specialises in special needs? Well now there is one. At [www.bid4allneeds.com](http://www.bid4allneeds.com) you can bid for loads of autism-related stuff second hand, and a percentage of earnings go to charity. Sister site [AutismNetwork.co.uk](http://AutismNetwork.co.uk), run by the same parent, who has a son with autism, looks pretty good, too!

Is your child over-sensitive to clothing? SmartKnitKIDS make seamless sensitivity socks which are now available in the UK through [www.Sensory-Smart.com](http://www.Sensory-Smart.com). Expect to pay about £6 a pair.

If your youngster craves movement, you may already be using a therapy ball. Bouncing on these are great for 'heavy work' which arouse the sensory system, but not so much that the child goes hyper. We LOOE [www.furriballs.com](http://www.furriballs.com), where you can buy fluffy covers for your therapy ball to match your lounge décor. Prices range from about £9 to £15.

A new coaching service for families is being offered to parents of children with autism, run by Claire Graves, who has worked as a family practitioner for Barnardo's. Claire has a son with ASC. The service isn't free and we haven't had direct experience of it ourselves, so would welcome feedback from anyone who uses it. Look up [www.jigsawfamilies.co.uk](http://www.jigsawfamilies.co.uk) or call 01773 825013 for details.

