

Autkids®

Issue 15
Spring 2012
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Positive Parenting for Children with Autism Spectrum Conditions



Overnight Success

Sleep advisor shares
sound advice



Smear Campaign

What to do when
they play with poo!



The Magic Compass

Making Social Stories™
work for your child

PLUS

SPECIAL OFFERS
on Rackety's clothing...



...and sleep
workshop!



Letter from the Editors



Hi and welcome to
ISSUE 15!



Time Specialist Support

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

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

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



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Cerebra

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A NATIONAL CHARITY IMPROVING THE LIVES OF CHILDREN AND YOUNG PEOPLE WITH NEUROLOGICAL CONDITIONS, THROUGH RESEARCH AND ON-GOING SUPPORT



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- Wills and Trusts scheme
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- Regional Officer support
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The new photograph, for those who've never met us, shows co-editor Debby Elley and Tori Houghton, with Debby's twins Alec and Bobby, eight, both of whom have autism.

When we started up AuKids in 2008, it was to answer a gap in provision for parents of young kids with autism. This year, we're finally fulfilling a dream, having produced a Starter's Special which we're sending out free to diagnosis centres and support groups around the UK. The Starter's Special is our equivalent of a greatest hits album and we hope that all those receiving it as a freebie will get a welcome boost just at the time they need it.

With sponsorship from Time Specialist Support, Tori's autism babysitting and support agency, we've been able to print 5,000 copies of the magazine, so you can imagine what a mammoth task sending them out to centres has been. Here we have to say a massive thank-you to our distributor Tim Tuff, who has autism. His patience and fortitude in the face of hundreds of boxes and packing envelopes has been second to none. Tim, we couldn't have done it without you!

It's been an exciting time for AuKids. Time Specialist Support is now renting an office in Cheadle, Cheshire, so AuKids will share the space and we'll finally have actual office desks. Swoon.

The AuKids team has also been busy popping up at various autism events around the country. If you'd like some leaflets and sample copies for your event, give us a shout. We attended Positive About Autism's **Positive About Sensory** training in February and can highly recommend it. Positive About Autism now sponsors AuKids and so you'll find a double-sided leaflet featuring both organisations inside this issue. Please pass it on to anyone you feel would benefit from AuKids and why not sign up for a useful course at the same time?

We were also chuffed to star in The Independent's autism supplement on April 2nd. Our aim is to reach as many parents as possible, but no matter how we grow, we'll always keep that small and personal touch. That's what you like about AuKids, and that's why we do it. Keep in touch with us on Facebook and Twitter and please don't forget to keep sending in cute pics of your kids and ideas for features.

This issue tackles the delicate issue of poo. We've probably stepped around this for a while (bad phrasing) but when it affects you, poo play is such a tricky behaviour to tackle that we felt some expert panellists were required.

We also spoke to one of the UK's top autism sleep counsellors, Chris Hoyle of the Together Trust, about the question of kip and she's even arranged a discounted sleep workshop to follow up the feature with AuKids readers in mind.

The term 'Social Stories™' can be off-putting to parents as it sounds a bit technical. But once you know how to go about writing one, it's such an easy thing to do, can be prepared in minutes (sounding like Jamie Oliver, here) and is a massively useful tool for parents to have at their disposal. So resident speech and language therapist Tori Houghton is guiding you through how to write one. Read it, use it, love it!

So as always, practical, sensible advice from people who know about autism. Enjoy it...

See you in the summer!

Tori & Debby

COMPETITION WINNER FROM ISSUE 14:

The winner of the Sense of Calm DVD was Elaine Jones from Cheshire.



Front Cover Star: Tom Worgan

This picture was taken at Boomerang, a highly recommended sensory play centre for kids with disabilities located in Bury. Look up www.boomerangcentre.co.uk or call 0161 764 4842 for details, just £4 entry.



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

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

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A P P S

Grid Player

Free iPad App

This is by far one of the best **FREE** – yes, **FREE!** – communication aid apps which can be downloaded to your iPad. Grid Player has over 12,000 symbols categorised into different pages which are easy to navigate. It has a speech output button with two different voices as well as the option of just writing the words, which can then be spoken. Suitable for children who are currently using a visual support system such as PECS to communicate, this app gives the option of building on their existing expressive language skills. It can also be useful to help with understanding by supporting speech with ready available symbols.

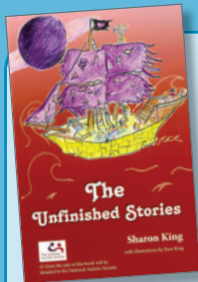
And did I already say it was free...?

Tori Houghton



Reviews

Youngster's Review



BOOK

The Unfinished Stories

By Sharon King
Published by Midnight Owl Books
£6.00 • ISBN 9780956741318

The Unfinished Stories is a magical and mysterious book. In the book Lesley Benedict's grandfather died and Lesley and her family visit his ghostly house The Nook. As well as babysitting her two annoying cousins Lesley finds lots of new friends and invents lots of new stories. In the attic sits a queen on a golden throne.

My favourite character is Stephen Brown – an autistic ghost who hates adventures. Although stuck in the past, Lesley helps him to escape the past and get on with being who he wants to be, a leader. This is the best thing in the book for me because it shows how different his life changed from being haunted by his terrible past and now being brave, happy and best of all adventurous – just like this book!

I would recommend this book to anyone as its weird but adventurous magic leaves you wanting to turn the page!

Lucy Pascoe, age 12.

Prize Comp!

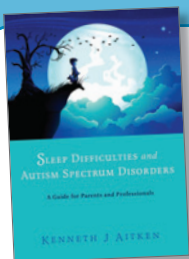
Author Sharon King is giving lucky AuKids readers the chance to win one of four copies of **The Unfinished Stories**.



Find the crown

As it features a queen and the author is a 'King', we've hidden a tiny image of a crown somewhere in AuKids. To be in with a chance of winning, simply write to us by May 31st 2012 telling us where the crown can be found. The first four readers out of the hat/crown will win a copy of the book. Our normal competition rules apply. Send your answers to aukidsmag@gmail.com with 'competition Issue 15' in the heading box, or on a postcard to AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE.

Editor's note: The Unfinished Stories is another mythical tale from Sharon King, mum to two children on the spectrum. She uses personal experience to bring autistic characters to life and daughter Rose, who has Asperger's, illustrates her novels. Rose also recently won a TV award for presenting a Newsround Extra on autism. The Unfinished Stories would appeal to youngsters between 8-12.



BOOK

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

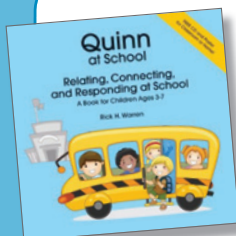
By Kenneth J. Aitken
Published by Jessica Kingsley
£19.99 from Amazon
ISBN 9781849052597

This is the first book that I know of dedicated to addressing sleep difficulties in ASC. The first two chapters of the book give a detailed account of sleep, what we know about it and what problems can arise in the population as a whole. The author then gives a detailed evidence based account of sleep problems in ASC followed by reasons why the sleep problems may occur, reflecting on issues such as the neurobiology of sleep, diet and metabolism and the insight that published studies offer into these possible factors.

The final chapter of the book focuses on possible interventions and the evidence base for them. This section includes guidance on how to keep a sleep diary, how to analyse contributing factors and lists sleep hygiene targets to aim for. The author then defines specific sleep problems such as difficulty settling to sleep, their incidence, documented interventions and the documented effectiveness of interventions. The book concludes with very comprehensive appendices on resources, medication, complementary approaches and assessment tools.

This book is a comprehensive and welcome resource for professionals in understanding sleep issues in children with autism, but parents looking for answers to their own child's problems may still need advice on the implementation of practical strategies.

Chris Hoyle, Sleep Counsellor, Together Trust (see Pages 4-5)



BOOK

Quinn at School: Relating, Connecting and Responding - A Book for Children Ages 3-7

By Rick H. Warren
Published by AAPC Publishing
£13.95 • ISBN 9781934575871

Language arts teacher Rick Warren wrote **Quinn at School** in response to a gap in the market.

In the author's note, he tells readers: 'My three-year-old son's central challenge was difficulty initiating or sustaining social contact. What I needed was a highly visual picture book that would help him begin to decode and use the non-verbal cues that make up so much of social communication. What I found was a disappointing lack of high-quality picture books in this area.'

So like a real trooper, he made one himself!

The result is a lively trip through a day at school, with pauses along the way to examine social situations and decide which of three choices is the correct response. The multiple choice is a really good idea – nothing is made too abstract.

Aimed at three to seven year olds, this covers people you meet at school and how to greet them as well as responding to situations at work and at play.

Quinn – whose smile is worthy of a toothpaste advert – makes talking about social situations accessible and attractive. Be warned, there are quite a few Americanisms, so you may have to adapt it slightly. Every situation should be related to your child's own experience to make the most of learning.

There's a handy CD-ROM version of the book included, which can be used as a PDF or converted for use on a Mimio interactive whiteboard system. Nice touch.

Debby Elley



BOOK

The Boy Who Fell to Earth

By Kathy Lette
Published by Bantam Press
£12.99 • ISBN 9780593060841

This book begins with single mum, Lucy, rushing to hospital after her 16 year-old autistic son, Merlin, is lying in a coma having been hit by a car. Regretting the last words she said to him, "I wish I'd never had you!"

Lucy then reflects back on her life bringing up Merlin after his father, Jeremy, walked out when Merlin was diagnosed with autism at the age of 3. Written by contemporary Australian novelist Kathy Lette, this book is based on her own experience of raising her son, who has Asperger's. The story is a good mix of hilarious anecdotes (especially when Lucy re-enters the dating scene) and real emotions that parents raising a child on the spectrum will be able to relate to and laugh at in equally good measures.

Tori Houghton

The

RIPPLE EFFECT



I personally have found it very humbling to work with children who smile so selflessly and brighten up what can seem these days such a hostile world.

Sarah Walls: Specialist Support Worker and Teaching Assistant



AS A PARENT, you're so dedicated to improving the life of your autistic child that one delightful consequence of it all may totally escape you. Our children enrich the lives of others. Because autistic kids can be hard to connect with, when they let a person get to know them, it can be wonderfully rewarding. We spoke to a range of professionals who work in the field of autism. We asked them this simple question: *What's in it for you?* The answers were deeply moving and prove something we've known for a long time: autism brings out the best in people.

Tori Houghton - Co-editor AuKids, speech and language therapist

Often when Debby and I are talking about autistic kids I end up saying how rewarding it is to be around them. Sometimes parents don't realise just how much their children enrich the lives of others. We felt it only right to share this information with you. It's not just about us helping them and being selfless – we get plenty out of this relationship, too!

My autism journey started in 1999 when I was fortunate to have a placement at a specialist nursery for children on the spectrum. As a first year speech and language therapy student I was keen and excited but apprehensive - I didn't know much about autism.

At the nursery, I was particularly drawn to a pre-verbal 4 year-old called Connor, seemingly lost in his own world. Although intrigued by him, I struggled to understand his behaviour and finding a way to communicate and connect with him became my goal.

On my placement, I spent as much time as I could with Connor, following his interests and copying his behaviours and sounds even before I was aware of intensive interaction techniques. One day, he arrived at nursery with his mum. As soon as he saw me, he jumped in the air and made some excited noises. Connor had captured my heart and from that moment on I was hooked....

After being the 'autism geek' at university, I qualified in speech and language therapy and have worked with autistic children of all ages ever since. Now I manage my own specialist support agency for young people with autism and support an adult as well as working as a speech and language therapist.

Every small step, every moment of connection, every communication signal still fills me with more satisfaction than any other job could give me. I'm always learning something new.

I still think about Connor who kick-started my passion for autism and how different my whole life would have been had I not met him at that nursery all those years ago.



Quentin and Adele

Adele Devine: Teacher, Surrey

'When I was 16 I volunteered as a helper on a holiday for children with special educational needs.

I knew nothing about autism, but was drawn towards working with one very special boy. He was non-verbal and quite challenging. He had the biggest smile and most beautiful eyes. I loved spending hours with him, sometimes just rocking backwards and forwards or copying his facial expressions. Without speech we were communicating and I felt very special that he had let me into his world.

'I knew there was an intelligent, beautiful spirit that was hidden from so many by his behaviour and lack of speech. I've never forgotten that wonderful introduction to what I now know as autism and finding my own instinctive way of developing intensive interaction techniques.

'I met my husband, Quentin, when I was in America working with adults with learning difficulties. Again I was totally drawn to working with the more challenging, non-verbal adults with autism. I just loved seeing them start to communicate. It made me think if I could work with children with autism I could play a part in changing the pattern of their lives.

'I went on to train and work as an ABA tutor and then to be a teacher at an autism specific school.

'If I'd never known that first boy and been allowed into his special world, my life would have taken a

totally different path. So you could say knowing that first autistic child changed the direction of my life, but also had a knock on effect on so many other children's lives.'

Want to know a spooky co-incidence? One of the pupils at the school where Adele works, Freemantles in Surrey, is that very boy who inspired Tori to become involved in autism in 1999. With Adele's help, Tori has been in touch with Connor's mum, Michelle, who had this to say about Connor, now 16:

'We are extremely proud of him, with all his problems he can still manage to laugh and find things hilarious. I am still amazed you remember my son and that he had such an impact on you and your life....but this just makes me even more proud of him and I would like to thank you so much for that, Tori.'



CONNOR THEN...



...CONNOR NOW



Hannah Bowes:
Specialist Support Worker

'Witnessing that breakthrough moment when you're not expecting it...brings a huge smile to my face. I get job satisfaction from the smallest of things, worth gold when working with a person with autism.'

'I have learnt to never give up, and try as hard as possible in the most relaxed, hands-off way, instead of thinking I've got to get an outcome straight away. It's OK to wait, it'll happen.'



Lindsey Entwistle:
Support Worker and Occupational Therapy Student

I find it fascinating how autistic children find their own individual and unique ways of communicating their wants and needs and I have learnt not to take non-verbal communication for granted, as it can be a very powerful tool. The subtle interaction that autistic children give can often mean big steps in their development which for me is so wonderful to see. From simple eye contact to a little chuckle or even just having them approach you - autistic children have so much to offer.



Steve Boyle:
Support Worker

'Working with autistic children has enhanced my life, because working in a patient and tolerant way extends to the rest of my life.'



Kathy Leadbitter:
Specialised Early Years Practitioner/ Research Associate

'I love the way many autistic children are complete individuals; they lead their lives without worrying about what other people think of them. Spending time with autistic people makes you see how ridiculous and arbitrary so many of our social rules and norms are.'



Kelly Conway:
Speech and Language Pathologist, America

'When I first starting working in the field of autism, I often thought that the diagnosis was the end of the world in so many ways for children. After 20 years, I see that I was wrong. Autism isn't the end of the world, it's just another way of living in the world. It can be beautiful, quirky, challenging, funny and inspiring.'

'Today, one of my students looked at me and said, "Bye, bye pig!"....to the uninformed, it would have been insulting. Little did they know that 'pig' is a compliment in this child's world. She likes pigs...and that was my biggest compliment of the day! My days are filled with equal parts challenges and laughter. I wouldn't trade one moment of the last 20 years.'

'It's amazing watching a young child with autism learn a new skill because every gain in their life was an uphill battle.'



Amalia Kostorizou:
Teacher

'Focusing on little sensory details when interacting with people is I believe a skill that children with ASC acquire. One such detail is people's facial changes and movements when they are happy, bored or expect something. I have noticed pupils observing these details. For example, laughing with an adult because his ears change colour or his face twitches when he gets annoyed by something.'

'To me, the way they see things resembles the way a film director zooms in and captures details of scenes and people. Then I reflect back on my own observation - *'Hang on, I have never noticed this redness in his ears.'*

'Another detail that children with autism sometimes respond to is the pitch and tone of people's voices. This makes me think about people's tone of voice and what meaning it may carry. Do I have the same urge to hide, walk away or even lash out when someone talks to me in an authoritarian manner?'



Francesca Sephton:
Support Worker and Speech and Language Therapy Student

'The most rewarding experience I have had from working with autistic children is developing a rapport with someone who really struggles to communicate. I have learnt that when one thing doesn't work, to try another and to persevere has brought about such fulfilling results.'

'One child who I work with was initially very withdrawn and upset but now smiles and waits for me at the window. For me, experiences like that put a massive smile on my face. I would like families to know that it is a pleasure to look after their children and give the family some time for themselves.'

In my work either as a personal trainer or as a martial arts instructor, I often find that I need to discover what makes an autistic child 'tick'. Once I do we can get some fantastic results! It's not often that any child will give so much enthusiasm or energy to a task and that rubs off on me!



John Preston:
Personal Trainer and Martial Arts Instructor

PERSONAL STORIES

Mavis Wilkinson: Bobby's Lunchtime Assistant

'We have some fun together, it gives me an opportunity to sing, laugh and joke working with an autistic child as their lunchtime supervisor. I love coming to work to be with him. I have been there right from the start when he joined the school and what's rewarding has been seeing the way he has developed socially and I enjoy his happy disposition!'



M'lanie Seton: Bobby's Learning Support Assistant

'I love working with Bobby. It's rewarding to see how far he has come on, to hear him chat to his friends. I'm proud that he's managed to be in the school play, when I think how long it's taken to get there. He is an easy boy to be with once you know his funny little ways. I love his little sayings...like when someone has found the work difficult but then managed it, Bobby will run to the front and say: "It is like the beautiful swan!" It's hard not to rush Bobby when you are in a rush. I have had to learn to be patient, we need to understand that Bobby has to take his time and have his space.'



M'lanie and Mavis both work with co-editor Debby Elley's son, Bobby.

Ask the Experts

When Margaret's son decided to decorate his bedroom, the result wasn't quite what she had expected.



“ My little girl makes a mess with her poo and gets it on the walls. I am too embarrassed about it to seek help, but am getting pretty desperate. Is this a common problem with autism? What can I do? ”



Julia Dyer
MCSP BSc (Hons)

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

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

This is certainly not an uncommon problem seen in children with autism, and there could be many reasons for the behaviour, so it is difficult to give a short reply. I will therefore focus on only sensory reasons for the behaviour.

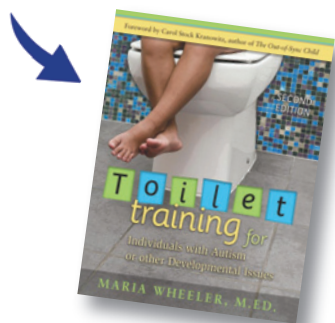
If this behaviour is happening during toileting, it may be that your daughter does not have the motor skills needed to wipe herself and therefore gets faeces on her hands when she is attempting to wipe her bottom. In order to wipe ourselves, we need to have a very good knowledge of where our hands are and how they are moving, as we do not get any visual information when our hands are behind our backs. When she then sees faeces are on her hands, she may well wipe her hands on the walls to try and remove it. She may not like the feel of toilet paper if she is over

responsive to touch and may therefore use her hands instead. You could provide wet wipes as an alternative.

If she is smearing at other times, it may be because she is seeking out tactile input and likes the feel of her faeces on her hands. In this case, you could provide her with plenty of alternatives during the day for messy tactile play, such as playing with shaving foam, sand and water play.

Another possible reason could be that she actually does not feel or is not sure that she has opened bowels and then is feeling with her hands to see if she has. This would indicate that she is under responsive to tactile information.

You may find the book **Toilet Training for Individuals with Autism and other Developmental Issues** by Maria Wheeler helpful reading.



Luke Beardon

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

First off - you are by no means alone, so don't feel that this is some kind of a shameful secret. It's a common issue for many parents and really the shameful aspect appears to stem from the fact that it's poo that is being smeared - there is far less stigma attached when autistic children (or adults) enjoy smearing less problematic materials such as paints. In all honesty this makes the whole thing a bit of a nonsense - after all, if one enjoys the act of smearing then what better material to use than one which is frequently readily available and almost always just of the right consistency?!

In many cases the smearing is directly and strongly related to a sensory experience - olfactory, tactile, visual - all can be wonderfully stimulated by a handful of poo and handy surfaces upon which to smear. Obviously, this kind of behaviour is usually best avoided - but the individual should not be denied their sensory stimulation either. In such cases it's usually best to go for replica rather than eradication. A designated 'smearing area' (large white board, for example) can really help along with readily available smearing materials - as noted above, it could be paint; various consistencies of clay can be great, too. Coupled with a close eye on the individual and encouragement to move directly from poo smearing on the wall to paint/clay smearing on the white board and this could be a possible way forward. Good luck!

Did you know that Temple Grandin, one of the world's most successful adults with autism, engaged in this behaviour as a toddler? She has written: "Between non-stop tantrums and a penchant for smearing faeces, I was a terrible two year-old."

"The assumption that poo smearers are just stimming, or having sensory fixations with the texture, smell, taste, overlooks the emotional gratification of being boss, having control, keeping the unwanted behaviours as one's own sense of power/territory..."*

Donna Williams, author, speaker and adult with autism

**Repetitive body movement*



Suzie Franklin
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Smearing can often be associated with autism. Because it's such a difficult subject to talk about, parents can feel very isolated. But this is not your fault and there are things you can do to improve the situation.

Because of their social interaction and communication difficulties, children with autism are unlikely to be aware this behaviour has such an impact on you or possibly even care about how that makes you feel!

- Remember they are unlikely to be doing this to 'wind you up' although it may not feel like that at times.
- It may be that the smearing started when they got some poo on their fingers and wiped it on a wall to get rid of it or they were having difficulties wiping their bottom.

Your child may see this nice brown, warm, soft pliable plaything as something that makes lovely patterns on the wall or feels squidgy in their hands, but all too often this ends up on the sheets and all over them, too. They could enjoy the sensory experience of playing with and smearing their poo. If your child likes a lot of sensory stimulation try and give them opportunities to get this in other ways –

- Sensory and fiddle toys
- Play-Doh®
- Shaving foam
- Gloop (water and cornflour)
- Light-up toys
- Trampolining

"Coprogenics involves the eating and smearing of faeces for pleasure and surprisingly 1% of the human population have apparently engaged in it at some time!"

Donna Williams,
author, speaker and
adult with autism.

- You could also request a referral to an Occupational Therapist who specialises in sensory profiling for support and ideas.

If they are smearing at night, think about what they are wearing and how easy it is to get to their poo. Some parents have creatively resorted to –

- Swimming costumes (secured at the back) so they can't take their nappies off easily or get to their poo
- All-in-one suits worn back to front so their children can't get out of them!
- EDITORS - or check out Rackety's advice on clothing (right).

Think about how you respond to your child when they have smeared

- Try to limit your interaction with them.
- Don't reward this behaviour with a warm bath if that's something they like.
- Try a shower if possible and get them to help with the clear up if that's appropriate.

Does your child know that this behaviour is not socially acceptable? Because of their difficulties with social understanding and communication, they won't unless they are told in a way they will understand.

- A visual schedule or Social Story™ (see Pages 10-11) will help teach what you want them to do and discourage what you don't want to see.

- Speak to your child's school, Speech and

Language Therapist or local autism team as they may have some visual supports you could try.

If you see your child smearing –

- Redirect them to an activity you would prefer them to do and praise this behaviour.
- Reward systems are really useful in motivating children and are a visual way of recording their achievements.

Remember, these behaviours may not change overnight, but gradually things should start to improve. Other parents can be a great source of support and ideas so don't be afraid to speak about this, you may be surprised how many families are going through the same thing.



GUEST EXPERT

Annabel McMahon
Managing Director

Specialist Clothing Company
Rackety's Ltd

Winner of the Big Venture Challenge 2011, designed to reward businesses that create social impact.

Web: www.racketys.co.uk
Tel: 01538 381430
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What's interesting from working here is when I get that phone call and a nervous mum asks 'Er, do you do those pyjamas...?' I can tell by the way they're not forthcoming that there's an issue going on in the background and so I tend to make it easier for them and I venture: 'Are they pooing and smearing on the walls?' I get a gasp of relief at the end of the line, because they think it's only happening to them.

They don't feel comfortable with the problem and they're so relieved to talk about it – I reassure them that I commonly get these requests!



Our products can help when hands are straying into nappies and kids are pulling things off, or if everything's uncomfortable because they're moving about so much. Our garments are designed to keep everything in place. So we have popper vests that do up easily and securely underneath the child, we have polo shirts with poppers that do up underneath and popper pyjamas – all for girls and boys aged from 3-14 and we do some vests for adults, too. Prices are from around £10 a popper vest and there are discounts on value packs. We're one of the few places that does them and they're a quality product – we put them through factories that are used to supplying high street stores, so they're high street quality. We can't guarantee that this will always work, but when it does, it's life-changing.



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CASE STUDY: Debby's son Alec used to wear Annabel's popper vests and popper pyjamas, which is why we featured them. "Although smearing wasn't a problem, in ordinary pyjamas he became very adept at removing his nappy at night. Once we had the popper clothes, we never had a problem at all, it was brilliant. He wore them for a year or two and by the time he was out of them, he'd entirely forgotten his habit. He's eight now and wears normal pyjamas."

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

Do You Work a 24 - Hour Shift?

ACCORDING to one piece of research, 86% of autistic children suffer from disrupted sleep*. Even when you consider the most optimistic figures, the incidence of sleep problems in autistic children remains far higher than average. Sleep counsellor Chris Hoyle talks to Debby Elley about why it's such a problem and offers some much-needed advice for exhausted families.



Chris Hoyle has been helping autistic children get a good night's sleep for over six years. Her specialist clinic, based at the Together Trust's Inscape House School in Manchester, provides a tailored approach for struggling families. This year, the clinic reached the final in the SEN Category of the Independent Specialist Care awards, which were launched in 2011 to highlight the best performing providers of social care.

The reasons for the clinic's success soon become apparent. Sleep clinics for children with ASC are notably rare. Also, most books tend to focus on sleep issues concerning disabled children in general, but Chris explains that autism itself plays such a major role in a child's sleep disruption that it has to be the focus of any solution.

"There's a lot we can do by looking at the child's autism and how it impacts on their sleep patterns," says Chris. "Sometimes we find that very small changes can actually have quite a big impact."

In Chris's parent workshops, she focuses on each recognised aspect of autism, talking about its impact on sleep and suggesting practical solutions.

Unsurprisingly, routine is the most important factor. Chris puts many night-time difficulties down to what she calls 'sleep hygiene' - the routine of getting the child into bed.

"Having a very set, logical bedtime routine is vital for children. Often when we work with families, we find that although they do have routines, they're not logical from the child's point of view."

For example, a parent might take their child upstairs to prepare for bed, wash in the bathroom but then put on pyjamas in a room that is neither their bedroom nor the bathroom. If the child then returns downstairs, the logical link between preparing for bed and actually going to bed is lost.

Chris explains: "Just strengthening that connection between preparation for bed and going to bed can have a huge impact on a child. I can't stress enough how important that is."

The second difficulty that autistic children can face is two-fold: a lack of understanding of the concept of time and a lack of understanding of the social rules that govern it.

"That's a huge factor, especially for children with limited language," says Chris. "Something that I've come to realise whilst I've been doing this work, is that a lot of children have night time waking or early morning rising because they don't know that if they wake up at 3am it's socially not the time to get out of bed."

"We have to teach them - these are the social rules, this is when morning starts. We have to look at different methods that suit the individual child to get that message across to him or her."

Chris uses two symbols to make the messages simple - 'time to sleep' and 'time to wake up'. Those are accompanied by a strong difference in a parent's demeanour, quiet and calm when

it's time for bed and bright and breezy in the morning.

Working with children who get up in the middle of the night, Chris studies two to three weeks of sleep diaries before helping parents to establish a block of sleep. She starts by giving the child a 'set waking time' which is only quarter of an hour later than the time at which they routinely get up, even if that's what she calls 'obscenely early'. If the child wakes before that time, they are shown the 'time to sleep' symbol. At the 'set waking time', the parent draws the curtains, switches lights on and says a bright and breezy: "Morning! Time to wake up!" This gives really strong social cues and visual reinforcement to teach the child the concept of morning.

At bedtime, as well as changes to sleep hygiene, a strategy called 'bedtime fading' sometimes helps. The child's bedtime is put back, for example from 7.30pm to

9.30pm. This tends to reduce night waking and a period of sleep is consolidated. Once this is established, the set waking time is gradually shifted. Parents have found that Chris's method has helped their child move from a pattern of just a few hours' sleep to a full night of unbroken bliss.

The value of other clear social signals shouldn't be underestimated, either, according to Chris. "In one family I visited, two daughters shared a bedroom. When I went in, I couldn't tell whose bed was whose. The beds were identical, the bedding was identical, so for a child with autism that was an added confusion. With no distinguishing features, it was very difficult for them to have

ownership of that bed. So we did a big symbol for the top of their beds with a photograph of each girl to make that very clear."

Sensory factors can play a big part in night-time waking. "We need to look at the child's bedroom, their bed and what the child's wearing when they go to bed. Are they too hot or too cold? Is the duvet falling off? Can it be something really simple - would a sleeping bag be better? Would they be better with a big sheet over the top of the duvet tucked in under the mattress to keep the duvet in place?"

Light - or lack of it - is also important. "Making the room dark is very important to having the child sleep well because that's when melatonin is produced in the brain so we need to get the room as dark as possible," says Chris.

The solution for kids who fiddle with curtains? Sometimes unscrewing lightbulbs can help. A more drastic solution for one family was to invest in triple glazing, with untouchable blackout blinds between the windows.



STEPS TO SLEEP:
Chris Hoyle with some of the visual tools she uses in her clinics.

*The prevalence of sleep disorders varies according to different studies, ranging from 40 to 86% (Giannotti et al., 2008; Honomichl et al., 2002; Krakowiak et al., 2008; Liu, et al., 2006; Olyane and Bjorvatn, 2005; Patzold et al., 1998; Richdale, 1999; Richdale, 2001; Robinson and Richdale, 2004; Schreck and Mulick, 2000).

In many cases, blackout blinds help to give the right signals when the time of year makes it confusing to understand that although it's light, it's night.

Chris also encourages parents to think about their bedtime routines as the time to put away daily distractions. "Many children have computers and televisions in their bedrooms. What social cues are we giving them that the purpose of the room is changing at bedtime? It might be that we discuss strategies for concealing toys - a locked cupboard or a blanket thrown over a TV to show the child that those things have finished."

For some children, distractions can take the form of worries. Using another visual strategy - a 'daily plan' to write down things that need to be remembered for the next day can help to put those worries to bed. Chris suggests building in a special time before the evening meal to discuss any worries.

Other important factors that Chris considers play a part in sleep patterns are daytime activity - or lack of it - and diet, where factors such as the caffeine content of fizzy drinks can have an impact.

One element that may not have occurred to you though, is you. If you're present as part of the child's settling pattern and they need you there to get to sleep, the chances are that when the

child wakes, they will once again need you to settle.

"We'd always try and work on encouraging the child to settle to sleep on their own at night without a parent present," explains Chris. This can mean simplifying quite complex routines so that the child is not reliant on repeating them in the middle of the night to resettle."

Does it sound daunting? Anxiety over making a change is understandable but usually unfounded, says Chris. "That's often the reaction you get from parents, even though the situation can be really horrendous. They're frightened that if they try and change it, that it might get even worse. So a lot of parents need reassurance that it might get worse for about three nights, but then the behaviour gets better and better."

"Time and again, parents have told me they're so surprised to find out how painless it is to solve a sleep problem."



Top Tips

From Chris' Sleep Clinic

STAR STUDDED: Use reward charts themed on a child's major interest to reinforce good behaviour such as not disturbing anyone before waking time. Once a simple reward has been established for staying in bed one night and it's consistently happening, move the reward so that it's for four nights, but maintain it.

LET'S FACE IT: Clocks made by Worlds Apart are a great visual way to train kids, as their faces change from night to day. The Go Grow Sleep Trainer by the Gro Company is also a sleep training clock, but with simpler images suitable for pre-verbal kids. Available from Amazon at £20.89.



PICTURE PERFECT: Make your own visual timeline, outlining the entire bedtime schedule, to reinforce your bedtime routine. This can help kids to realise that they won't eat till morning.

SIGN LANGUAGE: Use bedroom door signs to reinforce ownership and 'no entry' ones on bedrooms that your kids are not allowed into.

BOX CLEVER: For a child who takes worries to bed, use a cash box with some coloured sticky notes and a nice pen to record the worries, fold them up and lock them away safely to be discussed tomorrow. Or chat about them before the evening meal, not at bedtime.

EARLY BIRD: If you have an early waking child, reconsider the time they're going to bed, it could be too early.

EASY DOES IT: Simplify prolonged settling routines so that the child is able to settle on their own at bedtime and on waking in the night.

BOOK IT: To book a private consultation with the sleep clinic, contact choyle@togethertrust.org or call 0161 283 4750. To find out more information, look up www.togethertrust.org.uk. Alternatively, sign up for Chris' parent workshop (see advert), arranged especially for you with a discount for AuKids readers! For details of future workshops, contact Chris at the e-mail address above.

READ IT: Oh joy, just as we were putting this feature together we discovered a brand new book. **Sleep Difficulties and Autism Spectrum Disorders, A Guide for Parents and Professionals** is written by Kenneth J. Aitken and available from Jessica Kingsley Publishers priced £24.99 (see page 3).

Together for autism

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

Together Trust ASC specialist services include:

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



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

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Sleep Workshop

Want to know more? Chris Hoyle is holding a sleep clinic workshop on June 21st at 10am-2pm at the Together Trust in Cheadle, Cheshire. The usual cost of the workshop is £15 but AuKids readers can get a third off and book it for just £10! To book, contact choyle@togethertrust.org or call 0161 283 4750, quoting 'AuKids offer'.

together
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Maps of the Social World



Using Social Stories™ to Help Your Child Navigate Their Way

To autistic children, social skills are uncharted territory. It seems that everyone else is carrying a map, but they haven't been given one. Knowing what's expected of you in hundreds of different social situations can be terribly confusing. The Social Story™ is a simple tool that can be easily overlooked, but if you were going somewhere new, you'd take a map. By creating Social Stories™, you're doing the same for your child. Our resident speech and language therapist Tori Houghton shows you how...

What are Social Stories™?



Carol Gray

Social Stories™ were developed in 1991 by Carol Gray, Director of The Gray Center for Social Learning and Understanding in Michigan. They are written or visual explanations of social situations. For example, take going to the dentist for the first time. Someone might explain to you how you would go up to reception, give your name, wait in the waiting room and your name would be called. Once with the dentist you would have to open your mouth and so on...

You wouldn't be told how to behave, but you'd be given a verbal explanation of what to expect.

Social Stories™ are based on a similar idea, but instead of *talking* about what is going to happen, the explanation is a written one. As the famous autistic speaker Ros Blackburn has said, never assume that someone with autism knows the score. Stating what seems like the obvious may feel a bit patronising to you, but can make life very much easier for them.

When Do We Need Them?

Social Stories™ can act like a stitch in time. If you know that a small change, or a bigger one, is going to cause anxiety or stress, a Social Story™ is a good way of preparing your child for what's going to happen in a very neutral and calm tone.

Social Stories™ are also good for preparing kids for what's expected of them in totally new situations, for example going to a wedding ceremony. But they're also a great tool for daily challenges and can be used to explain what the 'rules' are for stuff like going to a public toilet or to a library, where a lack of knowledge may make them behave inappropriately or cause them distress.

Having a step by step explanation beforehand is far more effective than trying to tackle problems when you're in the middle of them – for you and for them! As a parent, it does mean thinking about a situation before it occurs and then preparing a Social Story™ to nip any concerns in the bud.

For all sorts of kids on the spectrum, it's really useful and once you've written one or two, they'll become second nature.

Why Do We Write It Down?

We know that most autistic people generally respond better to visual information. It's permanent, predictable and reassuring and can be consulted and re-read to ensure understanding.

Be Prepared!

Think of this as a compass and map for your little Scout, helping them to navigate through the confusing world of social situations. The Social Story™ explains the theory behind our sometimes bizarre social behaviours – what is expected and why. When we plan a trip abroad what's the first thing we do? Get a guide book! We read up on the kind of behaviour that can be expected in a different culture. Then we know what to expect. Overall, life is less stressful when you're well prepared.

I'm No Poet...

You don't have to be. It's as simple as writing a shopping list, just follow our step by step guide below.

So What Does A Social Story™ Look Like?

A Social Story™ About A Social Story™

I often need to explain to my autistic child what is going to happen in a social situation and what is expected of him. **(DESCRIPTIVE)**

This is like when I go to an appointment and someone needs to explain to me what to do. **(CONTROL)**

Social Stories™ are a way of describing to him what is going to happen and why in different situations. **(DESCRIPTIVE)**

Social Stories™ always contain more descriptive sentences than directive ones. **(DESCRIPTIVE)**

This is very important. **(AFFIRMATIVE)**

I will try and use more descriptive sentences in my Social Stories™ to help my child understand the world around him. **(DIRECTIVE)**

KEY - Main Types of sentences:

DESCRIPTIVE: Answers the "wh" questions and describes the situation from an objective perspective.

CONTROL: Compares this situation with a more familiar one, providing personal meaning by using the child's interests or previous experiences. You might well use the phrase: "This is just like when....."

AFFIRMATIVE: A reassuring nod to the child's anxieties - it enhances the meaning, 'this is ok'. E.g. *I might feel a little unsure about this at first. This is okay, I can take my time.*

DIRECTIVE: Usually near the end of the story, this positively and flexibly offers a response usually in the form of "I will try to....." We use the word 'try to' to allow for errors and avoid rigidity.

What If My Child Doesn't Read?

It's important to tailor Social Stories™ to the right level of understanding for your child. You can read the story to your child or s/he can be shown through a picture version. Social Stories™ only really work with children who have some understanding of language. For those who struggle, simple pictures or symbol strips are more effective.

What Makes It A Proper 'Social Story'™?

Social Stories™ follow a particular format as identified by Carol Gray. The format is carefully balanced so that the child receives gentle, clear explanations and is steered in the right direction rather than dictated to. The Social Story™ is constructed to connect with a child on their level and to avoid applying any pressure. The way that they're constructed means that autistic kids can readily take on board the information in them. Finally, to avoid confusion, they're aimed at explaining ONE thing only, not several situations or responses at once.

The Format – A Social Story™

1. Has a title, to orientate the person straight away
2. Has an introduction, main body and conclusion
3. Answers "wh" questions
4. Always uses positive language
5. Is written in 1st or 3rd person perspective
6. ALWAYS contains descriptive sentences
7. Contains twice as many descriptive sentences than directive ones – 1 directive sentence to every 2-5 descriptive/affirmative ones

8. The format is tailored to the person's level of language
9. It may include illustrations

How to Introduce a Social Story™

Depending on your child's level of understanding, it's important that they understand that it's their story. Personalise it, use examples of their interests in the story e.g. like when Numberjack 4 is late..., and enlist their help in making it colourful. Read the story well before the situation is going to happen and have it available for future reference.

Social Story™ Everyday Example:

Going to the Supermarket

Sometimes I go to the supermarket with mum.

I like doing the shopping with her.

Sometimes if I walk away from mummy when she's busy, she can't see where I've got to. This makes her worried, like when Numberjack Five lost Numberjack Zero when they were out and about.

Staying close to mummy in the supermarket is really important because it keeps me safe and it stops me from getting lost. It also makes mummy feel really happy and proud of me.

I will try and stay close to mummy when we are in the supermarket.

Further Information

Book: Carol Gray – My Social Stories™ by Carol Gray and Abbie Leigh White, contains lots of example stories.

Factsheet: NAS – How to Write a Social Story™. Look up www.autism.org.uk

Websites:

www.kansasasd.com has example social narratives that you can use and adapt to your child (click on 'classroom materials' under 'explore more resources').

Carol Gray's website includes a video of her talking about Social Stories™:

www.thegrayscale.org/social-stories/what-are-social-stories

www.haringey.gov.uk/what_are_social_stories.pdf

Apps:

'Going Places' app – it's American but it can give Brits some ideas.

'Touch Autism' apps – Social Stories™ about asking questions, using words etc.

Aukids likes...

Triple Stories

This American computer software is easy to use and brilliant for creating a range of visual support such as Social Stories™. It enables you to add in your own photos or choose pictures from a database of over 500. Pictures can be edited and you can add in your own text. Stories can be printed out, emailed, personalised and loaded to your smartphone or tablet. The software comes with plenty of examples to help inspire you.

For more information:

www.triplestories.com

\$99 for parents (currently £62.50)

\$129 for professionals (currently £82.00)

Free worldwide shipping.

Autscape

An autistic conference

23 July – 26 July 2012

Autscape is an *autistic* conference. It is created primarily *for* autistic people of all ages. It is also organised and run *by* autistic people. This year's theme is 'Similarities and Diversities'.

- ◆ Autistic-friendly environment
- ◆ Non-autistic people are also welcome
- ◆ Childcare programme
- ◆ Workshops and presentations
- ◆ Meet others with Asperger's and autism
- ◆ Leisure activities
- ◆ Quiet location with plenty of outdoor space
- ◆ Affordable fees
- ◆ Full board – 3 meals and tea/coffee breaks included
- ◆ Some diets catered for

Where: Belsey Bridge Conference Centre, East Anglia, UK

When: Monday 23 July – Thursday 26 July 2012

Info: Phone: 0775 400 5873 (Trish)

Post: 24 Anson Road, Upper Cambourne, Cambridge, CB23 6DQ

Email: info@autscape.org

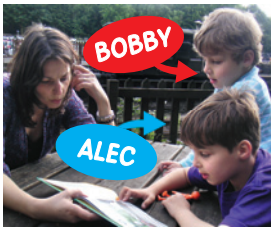
Website: www.autscape.org

Registration is open until 30 June.

AUTSCAPE

The Autscape Organisation. Registered charity no. 1141913, Company no. 7325467





The Last Word

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

When Honesty is the Only Policy

Bobby's always been into adverts. The latest is www.justeat.com. Just Eat is an online broker for local takeaways. Bobby loves the animated advert, which involves a dim, greedy 'belly' desperate for some food and a wise, more considered 'brain' who has it all sussed at the touch of a button.

Over the years, I've started to admire Bobby's appreciation for adverts as works of art rather than sales vehicles. Once seen, an advert is never forgotten, and we can't drive through the nearby village of Gatley without highlighting every 'Just Eat' logo along the way.

There's a slight drawback. "Hmmm, this is a lovely takeaway," Bobby says, after I've placed a lovingly prepared home-cooked meal in front of him. I'm delicately trying to ignore the fact that he's reporting his love of fast food to all the staff at Outwood Primary School, which prides itself on 'Healthy Eating Status'.

Bob's love of adverts isn't unusual for someone who's autistic. That one-minute snippet is just enough to digest, remember and recall. It seems ironic, though, that someone who's incapable of twisting the truth would enjoy a medium that stretches the imagination to its farthest reaches.

Imagine if Bobby grew up to be an advertising executive. I can see the slogans now...

You won't look younger, but at least you'll feel as if you're doing something about it.

It doesn't clean stains all of the time, but when it works it's pretty good.

Drink this and you'll feel really glamorous and attractive. You won't look it, but you'll feel it.

It's a car with a few more gadgets than yours. I wouldn't drive it up this mountain though, you'll only stall and you're rubbish at hill starts.

The thing about Bobby, and most autistic kids I'd imagine, is that they're a salesperson's dream. He can't for the life of him imagine why someone would fib or misrepresent something. His eyes shine with excitement at

every new TV advert. When a cleaning product springs from a cupboard, he repeats their slogans with a sort of religious reverence.

They say a fool and his money are soon parted, but I reckon an autistic genius and his money will be in much the same situation if I don't get very good at writing Social Stories™ to explain that the world is full of conniving garbage-touting thieves.

"Trust me, Bob, it's rubbish," I tell him whilst watching some highly breakable product being whizzed around an unlikely-looking TV backdrop, the sort that any normal bedroom couldn't hope to provide.

"Can I have it?" asks Bob, totally ignoring me.

"Mummy has lived through all this stuff," I explain to him, sounding like a hateful, cynical parent. "Honestly, it's rubbish. It'll break. They just want your money. It's their job to sell you stuff."

I realise that trying to explain consumer capitalism to an autistic eight year-old may not be the most promising way to start a weekend.

Still, whether we like it or not, I'm not sure the world's quite ready for Bobby's advertising agency. At the moment, his ambition is to open a computer store, called Bobby's Screens. I dread to think of his advertising...

BOBBY'S Screens

If you can find cheaper elsewhere... go elsewhere, then.

Also by Debby Elley - Slings & Arrows, available £7.99 from www.lulu.com



COVER Star

TOM WORGAN

Age: 4 **I have:** Autism

I live: In Lancaster, Lancashire.

My family: Mum, Dad and brother Stephen, aged 5.

I like: Cars, trains, sensory play (Play-Doh®, PlayFoam™, bubbles,) computers, Cheerios, letters, numbers and books (my favourite story is 'We're Going on a Bear Hunt').

I don't like: Busy crowded places, not being able to do what I want to do.

Me in four words: Independent, loving, unpredictable and energetic.

If I were Prime Minister: I would make Early Years Intervention available to all children as it has helped me at home and nursery.



Cygnet Health Care

Autism and Asperger's Syndrome Services



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

OUTREACH SUPPORT:
For individuals aged 5-64.

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

PARENT SUPPORT FORUMS:
Providing advice, resources and the chance to meet other parents/carers.

CYGNET'S OTHER AUTISM SERVICES INCLUDE:

Springside South West, Exeter: Outreach support services.

The Springs Community, Kent: Residential care for individuals aged 16-64.

The Springs Unit, Harrow: Secure inpatient care for adult males with autism & Asperger's.

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

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

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www.aukids.co.uk



Think green! Recycle AuKids



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.