

Autkids™

Issue 9
Autumn 2010
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Positive Parenting for Children with Autism Spectrum Conditions



Stranger Danger

Our panel on staying safe



My Brilliant Brother

Growing up with an autistic sibling

Autism in Africa

Co-editor Tori meets autistic orphans in Uganda



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Letter from the Editors

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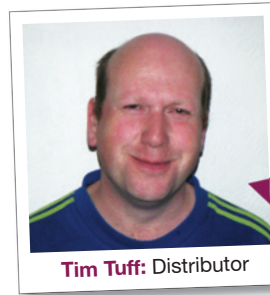
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Hi and welcome back to

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Tim Tuff: Distributor

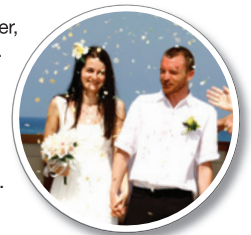
Tim is an adult with autism and he helps us with research and distribution. More about Tim next issue. A big thanks to him!

HERE it is, this is autumn. Ahead of us, we face long cold evenings and endless rain. Hold on, didn't we just have all that for summer? Oh well, here's another cracking issue of your favourite autism magazine to cheer you up.

We couldn't let Tori go to Uganda without passing on the wisdom of her experience with autistic orphans, so Debby officially interviewed her before anyone else could get a look in. The plane had barely landed before Debs had shoved a tape recorder under her nose. It seems we have a lot to be grateful for. Sometimes we're so busy fighting for services that we barely notice just how good the British system is in terms of provision for autism. And as far as we can tell, nowhere else has anything that can even touch the services provided by our very own National Autistic Society.

We've got a great Ask the Experts on stranger danger. People do tend to assume that autistic children are withdrawn, but sometimes the opposite is the case and, since they lack the awareness to process more subtle behaviour, we need to know how to protect them. Don't forget to e-mail us if you have a question for the panel, at aukidsmag@gmail.com

A quick congratulations to Jo Miller, our graphic designer, who got married in Cyprus in July and is now officially... dah dah dahhhh...Jo Perry. Jo, we wish you and Paul loads of happiness together.



We had loads of entries for our Thomas Land competition, thanks so much to all those who spotted correctly that Thomas appeared on Lula's slide, Page 5. Our winners were Max Churton, ten, from Cheshire and Joel Keys, seven, from Lancashire.

We had what can only be described as a *disappointing* number of entrants for our keyring competition. That was...er...zero entries. We can only assume that either none of you are very musical, or you were so totally engrossed in the wisdom of the article that you entirely forgot to enter. Or, ok, you weren't fussed about winning a keyring. So if you enter our Dear John competition this issue and you're a runner up, you know what you're getting, don't you?

Finally, we'd like to thank Standard Life for printing Aukids for us. Without them, we wouldn't have got off the ground. Sadly, it's now time to part company, as they can only help out for a maximum of two years. Thanks to a generous donation from Cygnet Health Care, we are able to print in 2011, but extra sponsors are always welcome to help us with our production costs.

All the best, and see you next year!

Tori and Debby

Our front cover star is Moses, see spotlight Page 4.

EDITORS: Tori Houghton and Debby Elley
PHOTOGRAPHY: Jennie Fielden BA (Hons)
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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.

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Jump Space - a charitably-run trampoline club for children with disabilities - opens a brand new centre in Cheshire this month.

The Stockport-based club will use trampolining, rebound therapy and play as its focus activities. Staff specialise in working with people with autism, using the trampoline as a means to unlock potential and for free expression.

The centre's accessible play space will include a slide, swing, mobility maze and a sensory room.

The centre caters for ages six and up and for all disabilities. Siblings are also welcome.

Parents can also relax and have a drink in the Jump Space café.



A launch day is being held on October 24th from 10am-5pm featuring a sponsored bounce for existing members and taster activities. Newcomers are invited to come along and talk to experienced staff about lessons.

Trampoline and rebound classes take place from 4pm-10pm Monday to Friday and during the day at weekends. Classes last an hour and cost £5 for under 18s, paid termly.

There is a £25 annual membership fee per person for classes.



The centre and play space is also available for group bookings during the day - please enquire to find out more.

Jump Space's new centre can be found at 2 Hardman St, Chestergate, Stockport, SK3 0DJ (near the famous 'pyramid' building).

For more information on sessions contact info@activejumpspace.org or look up www.activejumpspace.org.uk

New Site Takes Tips From Parents

A new website launched last month offers parents and professionals working with children who have learning disabilities a unique opportunity to swap handy, practical tips.

Netbuddy pools the expertise of parents, carers, teachers and therapists to provide simple but ingenious solutions to everyday issues. In addition, there's an interactive forum where people can solve specific problems together or share personal breakthroughs.



THE NETBUDDY TEAM: (left to right) Deborah Gundle, Linda Goldberg and Emma Sterland

Netbuddy Co-director Deborah Gundle, whose son has learning disabilities, said: "The idea for Netbuddy came about when my son was small. I spent so much time and energy solving day-to-day problems, which I felt sure other people had overcome before me. I had no idea where to go to find the solutions I was looking for, and I started to think it would be really useful to have a handbook."

Deborah's original idea developed into the concept of a website where people can contribute new tips and create an ongoing resource. "People are always giving each other advice on forums all over the net and in local

support groups," she explained. "We wanted to compile and categorise all this fabulous advice to make it easily accessible to the people who need it."

AuKids will be teaming up with Netbuddy for the magazine's website, revolving Netbuddy's top tips relating to autistic children on a daily basis.

Netbuddy also includes regular features on topical subjects such as benefits, home programmes and respite care. Plus, there's an opportunity for people to share their home videos and download useful, inspiring or humorous clips.

Linda Goldberg, Deborah's Co-director at Netbuddy and co-founder of Cosgrove Care, said: "We want to encourage people to celebrate their happy stories and achievements within a community that understands and appreciates the hard work that has gone into those successes."

Netbuddy organisers are calling for people to come forward and help make the website into a success by sharing their tips and ideas.

"Netbuddy is all about people getting involved," said Linda. "We want to be the place people come to find advice, help others and connect with like-minded people who understand learning disabilities."

Patricia Myers, Education Officer of the National Autistic Society, South Kent, said: "Tapping into parent/carer hands-on experience is immensely valuable. Nobody really knows how to cope with the day-to-day nitty gritty unless they've experienced it personally. I think Netbuddy is such a great idea."

If you have any tips you would like to share, please send them to the Netbuddy team at: emma@netbuddy.org.uk or call Emma on 020 7443 5156 Mobile: 07922792904

For further information, go to www.netbuddy.org.uk or e-mail netbuddy@netbuddy.org.uk



For more Netbuddy, see the back page.

Mobile App for Autism

At last - a group of researchers in the USA have made use of up-to-the-minute technology to help children with autism.

They've developed PixTalk, a software programme that works on any Windows Mobile Smart-phone. Teachers and carers can use a website connected with the software to make a selection of images from an online library that can be downloaded onto the phone.

Kids can then browse and select images to express themselves. Case study results indicate that PixTalk could be used as part of ongoing therapy.

This application also seems to have been marketed as a tool for making yourself understood clearly in a foreign country or where there are language barriers.

To download the programme, go to www.communicationautism.com The software is available free of charge and will work on PDAs and Smart-phones that run Windows (not Blackberries or Palms). The target group is for very young or severely autistic children.

Scanning Software Paves Way for Better Diagnosis

In August, research into autism made the headlines as it was reported that a team from London's Institute of Psychiatry had developed a brain scan that can be used to diagnose autism in adults. The 15-minute test that the scientists have devised could eventually lead to better diagnosis in children.

Facial recognition and hand-writing recognition techniques have been adapted for the new software so that it can 'learn' patterns typical of the autistic brain.

Imaging techniques are used to construct three dimensional images from the scans that can be analyzed for structure, shape and thickness. It is these biological markers that are used to assess whether or not a person has an autism spectrum condition.

Areas of the brain typically affected by autism are highlighted by the brain scan, including language and communication areas, areas associated with facial recognition and sensory-integration and areas that control aspects of social functioning.

The study, which was funded by the Medical Research Council, compared the brain scans of 20 adult men who had previously been diagnosed with autistic spectrum disorders, with scans of 20 brains of men without the condition. The findings were published in the Journal of Neuroscience. It is hoped that the NHS will be using the system within the next few years to assist better diagnosis of the condition in adults.

The method is cost effective, as no new equipment is needed, just a software upgrade for current MRI scanners. Studies will now be extended to include women and children.

Read all about it!

We don't have room to publish all the latest research into autism, but we know a place that does! Research Autism is the only UK charity exclusively dedicated to research into interventions in autism.

Its website reports on all the latest findings and newspaper reports, although it is at pains to point out that putting it on the site does not necessarily mean that Research Autism endorses the report. Find them at www.researchautism.net



Africa's Hidden Treasures



You'd think that working with autistic children on a daily basis in the UK would be challenging enough, without volunteering to travel to a place where some still believe that autism is witchcraft. Not for speech and language therapist Tori Houghton, as DEBBY ELLEY reports.

AuKids co-editor Tori spent this summer working voluntarily with autistic orphans in the south of Uganda. She travelled with Watoto, an organisation that runs a series of projects designed to transform the lives of orphaned children and vulnerable women in Africa. It was founded by two Canadian missionaries and is based on Christian principles.

Having teamed up with Philadelphia speech and language pathologist Kelly Conway, Tori started her trip by visiting one of the babies' homes in the capital, Kampala. The therapists then journeyed to one of Watoto's two orphan villages in the area.

The villages are designed to give orphans an ordinary childhood by replicating normal family life. They comprise a cluster of traditional African homes financed and built by volunteers. In these homes, up to eight children aged two and upwards are cared for by a mother figure employed by the organisation.

Watoto homes are designed to have running water and a bathroom, somewhat of a luxury in rural Africa. The villages themselves have schools, medical and community centres and are often situated in picturesque locations. For children who have been found abandoned in heart-breaking circumstances, this is just the sort of rescue that you'd hope for.

"What is lovely about the village is that all the kids look out for each other and there is a real sense of community," Tori says. "In the houses there's a real sense of family."

The children's village in Kampala has many children with disabilities. Orphans in Africa are often abandoned by large, poor families because of their special needs. Some are left

in hospitals or churches, others abandoned in far worse circumstances and are traumatised as a result.

Tori's priority was to visit Moses, a five year-old boy with autism who had charmed Irish volunteer Tara Justin a year previously. Tara and a friend, Jennifer McCarron, had funded Tori and Kelly's trip through fundraising from close family and friends.

At first, some of his carers hadn't thought Moses was autistic, because he was interactive and warm. Tori had to explain that autistic children aren't always withdrawn.

"He would run up and was like a limpet, climbing up and clinging to us and he was very sweet. On his first day, Kelly gave him a toy car and he went up to every friend saying: 'I have motor car. I have motor car.' And they said - 'Look - he interacts'. But it wasn't typical interaction, it was very repetitive and he didn't have that much understanding," she says.

"Anyone who is not behaving in the 'expected' way can be excluded from society"

Tori used games to demonstrate simple language. "One really great moment was when I was with Moses, playing with a balloon racer" - where you need to blow up the balloon and then hold the end and the car whizzes off," she says.

"Moses was such an independent little soul, but he couldn't blow up the balloon although he did keep on trying. After a while he handed it to his house brother, Sharif. I modelled 'Blow!' each time he did this and Moses started saying 'Blow!' Then we did ready, steady 'go!' and he copied this too.

By just modelling this language to Sharif, he began doing the same and rather than always speaking for Moses and doing everything for him as they did previously, Sharif began to hold back

in the balloon car game, waiting for Moses to say 'blow' and 'go'. It was really sweet, I hadn't actually told Sharif to do that, but he just kind of picked up on it."



Working with his family, Tori and Kelly highlighted Moses' needs. "However, when we were introduced to some of the other children in the village, we could see why Moses wasn't really their main concern," says Tori.

"There was another boy, also called Moses but we nicknamed him Mo. K. He literally bounced from person to person with this huge smile and big wide eyes. He'd launch himself at you in a way that was completely interactive, but with lack of control. He didn't have any spoken language just some vocalisations," she says.

"He wasn't in school and so his mum was with him all day long and she was really struggling. We tried him with a little rucksack with some bottles of water in just to centre him really and give him some proprioceptive feedback. That really calmed him and we suggested to his mum to let him wear the rucksack a couple of times a day."



Because of their behaviour, many children with autism are excluded from an education system that is too formal to adapt to their needs. "It's quite hidden out there, it's not openly spoken about, so people don't understand it. Anyone who is not behaving in the 'expected' way can be excluded from society," says Tori.

Then they met Godfrey, Tori laughs, who introduced himself as 'God'. "We called him Goddie."

Godfrey had also been excluded from school. "He had the best 'mum'. Since he was excluded she would sit at home and do work with him.



SPOTLIGHT

Moses

Age: 5

Diagnosis: Autism

Best habit: Giving the best kisses and cuddles!

I love: Cars, bubbles, gadget toys, iPods, music, dancing and mzungu (white people!)

Personality: Gentle, loving, serious and independent.

If I were Prime Minister: I would increase awareness of autism in Africa.

Song that best describes me: *Don't Stop Believin'* by Journey.



She was constantly praising him and when he did something right 'Good boy, Goddie! Good boy, Goddie!' High five, hug him.

"He was lucky that he was with her and that she really believed in him. So we suggested that 'Mamma Harriet' went to school with Goddie and sat with him just for an hour a day. They've got no equipment, so we bought lots of pens and paper and toys, but we suggested that school lends them materials."

Tori and Kelly also spent some time working with the teachers in the orphanage school. "Their understanding of autism was very limited. Because of the environment they work in, any child who has a difficulty is either considered severely traumatised - because some of them are - or stubborn, which can lead to them being kept home from school.

"We went through the **triad of impairments***. We had to tell them obvious things - that it wasn't contagious, a choice, or due to poor parenting. In the wider, less educated communities, it's seen as witchcraft and these children are possessed.

"Behaviour is very important out there. The education system is very formal, the classes can be huge - up to 80 children with no teaching assistants - and very directive. Watoto's tagline is 'raising future leaders' and for someone like Mo. K who isn't going to be a future leader, we were able to increase awareness about the quality of life that he could and had the right to have. They did really care for and meet the basic needs of the children with disabilities, but us being there helped to give them a voice."

The results of the teacher training were heartening. "By the end of it you could tell that they'd learnt something and were starting to think that just because the child's being difficult, it's not really within their control," says Tori.

"They realise more that they need to think of things from the child's point of view and be more flexible. We also helped them to see that you can't judge a book by its cover, and that lack of language does not mean lack of ability."

Those messages continued to reap rewards in the second babies' home the pair visited in Kampala, where disabled children were being looked after in a separate unit. Here, they came across Bethany, a six year-old girl with cerebral palsy.

Tori recalls: "Bethany was bright and could understand everything but had no means to communicate. So Kelly sat down with her one day and said 'How would you like a book full of pictures of all the things you can ask for?' She was so excited."

Bethany indicated the pictures she wanted through gestures. On the last day she was given her communication book and immediately asked to use her colouring book at the table.

"She was thrilled. She had a lot of promise. That was the hardest thing for me, seeing these kids and thinking how they could blossom back home."

Initially, the therapists' attempts to encourage **intensive interaction*** with the orphans were met with confusion. By the end of the visit, though, there was more understanding among teachers, parents and carers.



Godfrey

"In our culture we are used to repeating back to babies what they say, and we are used to tickles and rough and tumble. In African culture, physical touch and affection are a big part of interaction with children, however structured play and intensive interaction are much less familiar.

The trip, she concludes, achieved some worthwhile goals. "Even if it changed one person's attitude towards one child, it was worth it."

It's certainly reinforced her belief that Britain's system is one to be proud of. "Okay, over here we've all been looked at and I include myself in that - I've taken autistic kids out and been stared at, had comments, felt anxious and embarrassed - all of those things. But here our kids are safe, we get financial support, emotional support - there are places to go. Every child has a right to be educated in our country.

"We work really hard in our society to avoid trying to put a square peg in a round hole. We say, let's adapt the hole. Let's fit it around them. If someone needs to have a ramp to get their wheelchair up, we're not going to take away that ramp because they really need to learn to get up the step, are we? It's one size fits all in Uganda."

Overall, Tori is especially pleased that the trip succeeded in raising awareness of the condition.

"The best thing that we can do for our autistic children is to educate society and community about it. The more other people understand about autism, the easier their lives are going to be. Hopefully, having us there even for a month gave those autistic kids a louder voice."



Joseph and Kelly

For details on Watoto's work, look up www.watoto.com

*Balloon Racer, 99p, from www.sensorytoywarehouse.com

*Proprioception is the sense of where parts of our body are (without vision). We all have proprioceptor nerve endings in our muscles and joints. Proprioception allows us to be aware of our position in space and be able to time movement.

This sense also plays a part in the process of becoming alert or calming down. Proprioceptive input like the bottles of water is referred to as 'heavy work' because it requires us to use our muscles and joints in order for our brains to register the input. More weight means more information to the brain, which is why Tori's idea would have had a calming effect on Mo K's bouncy behaviour.

*Triad of impairments - often the simplest way of describing autism, it refers to the three key traits common to the condition - difficulties with communication, social skills and imagination.

*Intensive interaction is a technique often used by speech therapists and in therapy programmes for autism. It involves following a child's lead by joining in with what they are doing and copying their actions and sounds.

Thanks! Tori would like to thank the following people:

Firstly to Tara and Jen for inviting me into this project.

A massive thanks to David Hewitt and Sarah Forde from Intensive Interaction for donating all the DVDs and books which proved invaluable.

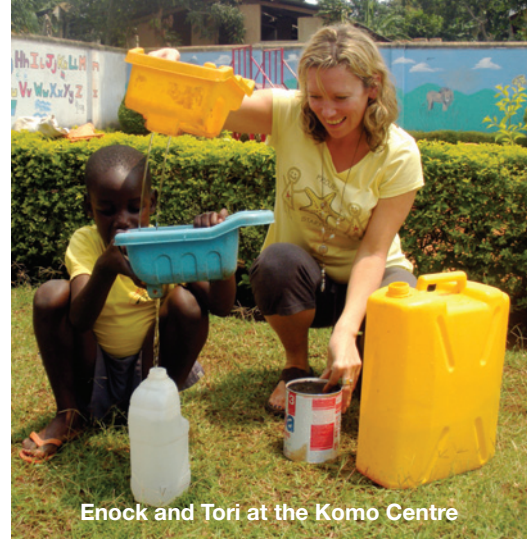
Huge thanks to Liz Howard at www.sensorytoywarehouse.com for the donation of fabulous motivating toys which the kids loved!!

To Watoto staff, particularly Hattie and Sarah, for making us feel so welcome in Uganda.

To Kelly - my co-pilot in this incredible journey. We worked well as a team!

To all to the wonderful Watoto kids who have taught me that a smile, a tickle and plastic toy car can go a long way!

And most of all, to you, Moses, who not only inspired this whole project but captured my heart from day one!



Enock and Tori at the Komo Centre

The Komo Centre ENTEBBE

Whilst on her trip to Uganda, Tori visited the Komo Centre. Having been impressed with what she saw there, she is now helping its staff with their fundraising efforts.

The Komo Centre is a ray of hope for families of children with autism in Uganda. Situated in Entebbe which is about 40 kilometres from the capital, Kampala, it's the country's only autism specific provision. Of the four to 13 year-olds catered for, there are currently nine children who regularly attend the centre and three who access outreach support. The centre also supports inclusive education by running a mainstream pre-school on site.

Set up in 2006 by Elizabeth Kaleeba, who was struggling to find appropriate education for her son Komo who has autism, the centre offers a calm, structured environment. The centre is managed by a UK special needs teacher who is working there through VSO (Voluntary Services Overseas), and staffed by locals, all ensuring that each child has an individual educational programme tailored to their specific needs.

Symbols are drawn, paper is limited and all toys are donated, yet despite this lack of resources, The Komo centre is a place to be proud of. Future plans include expansion, setting up vocational courses for older students and autism advocacy, helping to educate Ugandan communities about autism.

"Parents do feel really isolated. In their little communities, their child may be considered as the 'crazy one'," says Tori. "At the Komo Centre, they're trying to reduce the stigma of having a child with autism by providing more autism promotion and advocacy."

To find out more about how you can help the Komo Centre, go to www.komocentre.org or e-mail Anna Fayers anna@komocentre.org



"Until recently I was so delighted that my six year old autistic son was starting to socialise that I quite forgot about..."

Stranger Danger

Now when we're in the park, he strikes up a chat with anyone and he has no fear about how they might react. What's a good age to tackle this and how do I go about it?"



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.

You are right to be delighted by the fact that your son is now beginning to socialise. Before proceeding with my response, do not think that 'stranger danger' is something that you forgot to address. It is certainly not too late and in fact now that your son is socialising it may be considered the best time to begin this intervention.

I have worked with many children regarding this very issue. The best way forward is to write and introduce a thorough Social Story™* focusing on family, friends, friendships and the concept of strangers. When the

story is completed read this through with your son at least once a day. At the same time couple this with trips to the park and other social events and arenas. This way you can remind your son of the story and teach him within 'real life' situations what the story actually means.

Stories that I have written in the past have included:

- What is a friend?
- What friends do I have at the moment?
- What do friends do together? For example play dates, visit parks, cinema etc.
- People in my life that I can be affectionate with
- What are strangers?
- When can I talk to people that I don't know e.g. when my mum, dad, family member or teacher is with me.

Obviously this list is not exhaustive and what really matters when writing social stories is that you write it for your son. Include pictures of your son, his family and his friends. If you personalise the story, your son will be more likely to understand the concepts that you are introducing.

* See next page for guidance on Social Stories



Peter Lawson

Services manager at the Stockport branch of Cygnet Springside, a facility which provides specialist autism residential and outreach services.

Call: 0161 443 4060
Email: peterlawson@cygnethealth.co.uk

I think it would be a good idea for you to start to work with your son in relation to stranger danger as soon as possible; dependant on his level of autism, a Social Story™ may well be a good starting point.

When writing your 'stranger danger' social story, you will need to consider the level of your son's comprehension and potential anxieties. If he utilises PECS or similar, consider using them. Try to include passages (or pictures)

that are;

- Descriptive: What might happen?
- Directive: What should your son do when faced with the situation?
- Perspective: How might the situation make your son or others feel?

Try also to include how a situation relating to stranger danger might arise and some potential outcomes, focusing on the positives of avoiding potentially dangerous situations. Try to be clear as to who your son can talk to without them posing any risk and who might require caution.

Try reading the story with your son prior to his next visit to the park and make an assessment of his understanding of it. To help to reinforce positive behaviours, try initially reading the story with him daily and, as he gains an understanding of the risks associated with stranger danger, gradually decrease the frequency. Encourage your son to tell the story to other people, in order for it to become 'his' story and to reinforce it.

The views reflected in these columns are the panel's personal opinions and may not be relevant to all children with an autism spectrum condition. Parents should embark on intervention programmes only after following the advice of their child's paediatrician and/or occupational therapist.

Social Stories™ were developed by **Carol Gray**, President of The Gray Center.

A Social Story™ uses a specifically defined format to describe a situation or skill. The goal of a Social Story™ is to explain social information in a way that is clearly and easily understood by children with autism.



Carol Gray

President of The Gray Center for Social Learning and Understanding and Consultant to People with Autism Spectrum Disorders

As I am not directly involved with this mother and her child, the Social Story™ I have written is a general one. The child's physical, social, and emotional safety is central to the research, development, and implementation of every Social Story™.

What is a stranger?

As children grow, they learn about strangers. This is important to keep me safe.

I am growing. It is very, very, very important that I learn about strangers.

A person may be a stranger if:

1. This is the first time I have seen this person.
2. I don't know his name (from memory/without asking).
3. He or she is not in my Friends and Family Photo Album and Lists.

If I am with a carer and see someone who MAY be a stranger, it's important to follow these safety rules:

1. Talk with the stranger only after my adult carer, who is with me, talks with them first. Also, it's important to stay next to my carer.
2. Get a carer's permission first, before talking with a stranger.
3. Leave it to my carer to decide if we will tell the stranger my name, or where I live.

or otherwise of their communication.

It must not be expected that children with autism will be able to understand such notions, so a more black and white very clear structured manner of teaching needs to be employed.

Rather than using the term 'stranger' I would suggest a clear set of parameters, each with a directly taught response; after all - what is a stranger? Trying to accurately define the term can lead to considerable confusion. On the other hand, *has Mum/Dad given you permission to speak to this person today?* is a much clearer process with identifiable outcomes - i.e. if not, then you are not to speak to them. This obviously would not work with every child, it is simply an example of making boundaries much clearer for the child while not relying on the child's ability to make sense of a bewildering world.



Luke Beardon

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

It is imperative that children are protected as much as is possible, particularly when those in question lack an innate sense of who may pose a threat and who may not.

For neurotypical children a lot of protection issues rely on their conceptual understanding of essentially abstract intangibles, such as what constitutes a stranger, how the person is behaving, and the appropriateness

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E-mail us at aukidsmag@gmail.com

FAMILY FUN: Charlotte, Alex and Becca growing up in the Eighties



A Sibling on the Spectrum

Our Story: Charlotte and Becca

Interview by Tori Houghton

FAST FORWARD: Becca, Alex and Charlotte today



What effect does growing up with an autistic sibling really have on you? To gain an insight, I asked adult sisters Charlotte and Becca, whose younger brother Alex, now 25, has autism, to reflect on their childhood. What was good, what was bad...and what do they make of it all now?

"We both feel that we had a 'normal' upbringing and never felt that we missed out on anything," says Charlotte. As adults, both now with children of their own, they've come to recognise that their parents shielded them from a lot of their own worries, but it wasn't obvious at the time.

Charlotte, who is five years Alex's senior, has an early memory of things being 'different' when the family took a holiday in Lanzarote when Alex was about two.

"I just remember it being really hard work. Al used to run away all the time, we couldn't go to the beach as he would try to eat sand. I remember thinking that there was something a bit different and it had gone from being 'normal' to being hard work - particularly for mum."

Becca, the middle child, recalls when Al was in reception and she was in Year 2.

"He always used to play with me at play time. When I went up into Year 3 there was a yellow line and he wasn't allowed to cross it. It still chokes me up now as Al used to stand on the yellow line and watch me. I remember at that point knowing it wasn't quite right - that I had to look after him more than you would any other sibling."

Growing up, everyday life was different and everything was in a very strict routine.

"We had the same tea every night of the week, like cheese pie on a Wednesday. I can remember the times when my mum tried to make something different. All hell would break loose. Al would scream all night," says Charlotte.

The sisters became oblivious to the constant running up and down or incessant banging of doors.

"It was normal to us. Alex was completely in his own world and if you let go of him, he would just run. He would never say anything other than a question, with no eye contact. And repeat it over and over again. But it's funny because it didn't seem weird or different to us at all," says Becca.

The sisters had different relationships with Alex. Alex would always take Charlotte's side in an argument between the two sisters. "He would

always wade in and repeat whatever I said. I loved it as I always had an ally and I'd say to Becca - 'See, Al agrees with me!'" says Charlotte.

Yet when Alex struggled going to school and would lock himself in the bathroom, Becca was the only one who could encourage him to come out by putting on a silly voice and pretending to be French.

Charlotte remembers worrying about the future and trying to imagine an adult Alex. "My advice is not to worry too much about the future as everything has turned out so much better than we could have ever predicted," she says.

Neither could have imagined ever going on family holidays with their own children and their parents and having a nice time, but that's what happens now.

"We used to go to Abersoch in a caravan. Dad used to have to ride buses all day with Al. Mum would come and do stuff with us but we knew she felt bad for my dad," says Charlotte.

Becca says: "The relationship I have with him now is never what I would have expected as a child. Now we have a really good relationship. He lived with me for a year, lives round the corner from me now and I see him practically every day."

"Everything has turned out so much better than we could have predicted"

When asked what was the most difficult thing they had to deal with, both sisters say that it was the decision about Alex going away to college. They knew that an autism specific residential college would be the best way for Alex to learn to be independent, but the thought of not having him around all the time was heartbreaking.

"When he did go off to college, we thought we'd quite like it being the four of us - maybe get to do things that we couldn't have done before with Alex, and we did, but we didn't like it, it was like a massive hole, somebody was seriously missing," says Charlotte.

Alex now lives independently thanks to an incredible amount of hard work from his whole family who have fought for the financial support from Social Services.

He has regular support workers who help him manage day to day activities such as shopping and cleaning. He attends college courses in computers, Spanish and cooking and works for

the family business. Alex enjoys a fulfilled social life attending activities such as spinning classes at the gym and bowling. His sisters have taken over from their mum in managing all of his finances and support.

Becca says: "I know that Alex's life is a hundred times harder than everyone else's but I don't think about him having autism...He is who he is and he's fab. He's a brilliant uncle. My two year-old, Sam, just dotes on him."

Although the family has always been close, having Alex has meant that they all continue to work hard at making sure things get dealt with and that all decisions are made together.

"Having a brother like Al means that we have become very good at being in tune with each others' feelings," says Charlotte. "It's a given that we'll all stay together."

He Ain't Heavy, He's My Brother

The road is long
With many a winding turn
That leads us to who knows where
Who knows when
But I'm strong
Strong enough to carry him
He ain't heavy, he's my brother

So on we go
His welfare is of my concern
No burden is he to bear
We'll get there
For I know
He would not encumber me
He ain't heavy, he's my brother

If I'm laden at all
I'm laden with sadness
That everyone's heart
Isn't filled with the gladness
Of love for one another

It's a long, long road
From which there is no return
While we're on the way to there
Why not share
And the load
Doesn't weigh me down at all
He ain't heavy, he's my brother

He's my brother
He ain't heavy, he's my brother...

Written by Bobby Scott and Bob Russell

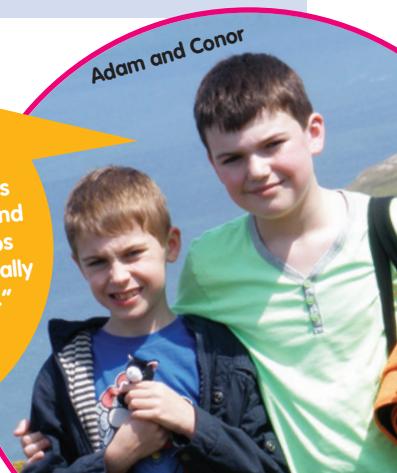
"Having brothers with autism has its ups and downs, but overall I think it's great. The best thing about my brothers is they have great characters and their presence is uplifting. The hardest thing is that it is hard to communicate with them and do normal things with them."

Masamba, 11, whose brothers Ebrima, six, and Omar, four, both have autism.



"I guess the best thing about Adam is that he is mentally younger than a child his age because of his disability so he has a laugh and a play with me and he keeps himself to himself and isn't really in your face like other kids."

Conor Giblin age 12, whose brother Adam is nine.



Extra Info...

Get Help

SIBS is the UK organization for sibs of disabled children and adults. The SIBS website recommends making a 'worry box' which can be filled with worries and questions. Parents may set aside time with the sibling to go through the worries and address them or put in return notes, whichever works best. Find them at www.sibs.org.uk

Get Clued Up

Contact A Family offers a guide for families about siblings of disabled children. Although it's not specific to autism, it is helpful in addressing a range of relevant issues. Download your free copy at:

www.cafamily.org.uk/pdfs/siblings.pdf



Get A Group!

Contact your local **National Autistic Society** branch to see if there are any support groups available for siblings - and request one if not.

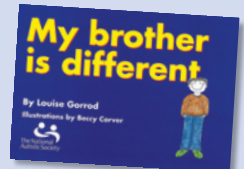
The NAS report that the Manchester siblings' group gave siblings time to spend with other people who understand their situation and are accepting of it. Even if they didn't directly talk about autism, it was often just an unspoken understanding. You can find your local branch at www.nas.org.uk

For any autism related issue call the NAS Autism Helpline on 0845 070 4004, or e-mail autismhelpline@nas.org.uk

Useful books

FOR YOUNGER CHILDREN

Published by the National Autistic Society



My Brother is Different

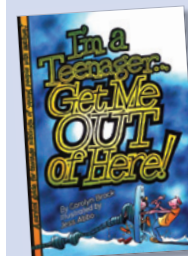
Author: Louise Gorrod Code: NAS233

My Sister is Different

Author: Sarah Tamsin Hunter Code: NAS641

My Special Brother Rory

Author: Ellie Fairfoot (aged six) and Jenny Mayne (Ellie's mum) Code: NAS543



FOR OLDER CHILDREN

I'm a Teenager Get Me Out of Here!

Author: Carolyn Brock

A survival guide for the teenage siblings of young people with autism.

"My brother George is so funny he does things that make me laugh and says silly things. I worry about him in case he has nobody to play with at school but I will always play with him."

Charlotte Fanton, age six.



Charlotte and George

"The best thing in life is never dull but the worst thing is, Dan doesn't know right from wrong."

Jack Wignall, nine, whose brother Dan, seven, has autism and epilepsy.



Jack and Dan

Expert Advice:

Q What can parents do to help siblings understand and when is the best time to tell them about autism?



Sandra Harris is a Professor at the Rutgers University and the Director of the Division of Research and Training at the Douglass Developmental Disabilities Center. Along with Beth Glasberg, she is co-author of **Siblings of Children with Autism** (available from Amazon).

Sandra Harris: I think the key thing in helping a child understand autism is to adjust what you say to your child's age and ability to understand. While one should not avoid using the word autism, in the presence of a young child, neither should we expect that it will mean anything to them. Young children will not benefit from a discussion of the details of autism, but they do need to be reassured about concerns about a sibling's behaviour.

For very young children autism is flapping hands, or not talking, or riding in a special bus to a different school. The one important thing to be attuned to for children who are four or five years of age is thinking that autism might be something a person can catch.

By six or seven children will begin to understand that their sibling on the spectrum has some very special needs and will begin to wonder more about autism. But they will still be focused on concrete behaviors more than on the social skills deficits and communication problems that are so salient to adolescent siblings or to us as adults.

As children get older they begin to understand about the biology of autism and realize that their brother or sister's diagnosis on the spectrum has significant implications for both the child with autism and the neurotypical sibling as they grow up.

STOP PRESS!

Being a sibling of someone with autism can present a challenge. Resources for Autism have a very successful siblings group in Birmingham and are about to launch a pilot group in London. For more information on the Birmingham group email heather@resourcesforautism.org.uk and for London email davina@resourcesforautism.org.uk

"Mark - he is my best friend!"

Jake Schofield, five, whose brother Mark, six, has autism.



Jake and Mark

From Me to You

Personal Advice:

Clare, whose 16 year-old brother Will has autism, has the following advice for siblings...

"Allow yourself to grieve for the brother or sister that you hoped you would have had. Perhaps that sounds strange but I have caught myself many a time in the early days wishing for that brother to appear, it took me a long time to accept that this was him. He has so much more to give than I could have seen back then, but it takes time to see that.

"Carve out one-on-one time to do something you both enjoy to build up trust and understanding.

Talk to someone outside of the family about how it makes you feel - you will find that more often than not they will find autism fascinating.

"Always think when you are in a difficult or embarrassing situation - 'I will find something about this to look back and laugh at one day', like the time he came leaping down the stairs dressed as Spiderman in two pairs of my tights when my new boyfriend came to meet him - priceless!"

"Having a bother with autism has made us (me, my sister and my other brother) far less selfish as brothers and sisters and as people. It makes you more accepting and see the world from a completely different point of view."

And Finally...

There is more on the NAS website

www.autism.org.uk/Living-with-autism/Parents-relatives-and-carers/Siblings.aspx

"Our sibling Oliver is only just over a year old! However, I think his worst thing is when he can't get his big brother's attention. I think his best thing is having a big brother who is always on the go and therefore provides hours of entertainment!"

Alli Palmer, mum to baby Oliver and Harry, four.



Oliver and Harry

"The siblings in our house are nearly two years old and nine weeks. The one who's nearly two does give Alex anything he wants when he gets upset over him playing with his toys. He just seems to know what his big brother needs and lets him have it - no questions asked. Kind of amazing really."

Lucy Ellis, mum to Charlie, nearly two, Alex (who has Asperger's), five, and baby Jack.



Charlie, Alex and Jack

Reviews

DVD **Dear John**

Directed by Lasse Hallström
Stars Channing Tatum and Amanda Seyfried



Whilst on leave from the US Special Forces, a chance meeting brings John Tyree (Channing Tatum) and Savannah Curtis (Mamma Mia's Amanda Seyfried) together on a sun-kissed beach at his home town. But they are torn apart when he returns to the army and she goes back to school, their only contact through a continuing stream of heartfelt letters, which strengthen their bond during a year-long separation.

Fate throws their love off course when the pair, at the point of reuniting, are separated once more by events surrounding the September 11th attacks. The world changes - and with it their romance - with heart-wrenching consequences.

Dear John is a touching tale of strengthening bonds through adversity. Although autism isn't central, the two autistic characters in it - a small boy and the father of the romantic lead (Richard Jenkins) - contribute to the notion that love in all its forms brings hope, strength and survival. The authenticity of Dear John's portrayal of the condition is partly down to Braeden Reed, who plays the role of the little boy and is himself autistic, and also down to the fact that autism isn't centre stage, merely an uncontrived part of the story.

Director Lasse Hallström lends this simple tear-jerker, based on the novel by Nicholas Sparks, a good degree of warmth and Dear John is told with restraint, neatly side-stepping any mawkish overtones that could have easily spoiled its more melancholy moments. Get ready to sob...even if you're a tough nut to crack.

Debby Elley

WIN DEAR JOHN ON DVD!



We have copies of Dear John to give away to four readers who can give us the answer to this question:

What was the name of the character that Amanda Seyfried played in Mamma Mia?

Answers to us at aukidsmag@gmail.com or PO Box 259 Cheadle Cheshire SK8 9BE by November 20th 2010. Winners will be selected at random after the closing date. Editor's decision is final.



BOOK

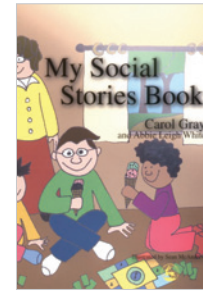
Banana!

By Ed Vere
2007
Published by Puffin Books
£5.99
ISBN 9780141500591

If your autistic child is non-verbal or has very few words, it can sometimes be a struggle finding books that aren't too babyish but have few words. So imagine my delight when rifling through the local library I found BANANA! By Ed Vere, a large book with great, bright cartoons which has just two words - 'Banana' and 'please'.

This humorous short story follows two monkeys as they fight for ownership of a single banana and (eventually) settle on a compromise. That's not before the BANANA! is demanded in many different tones of voice - it'll certainly bring out the actor in you whilst reinforcing one word and some very simple messages.

Debby Elley



BOOK

My Social Stories Book

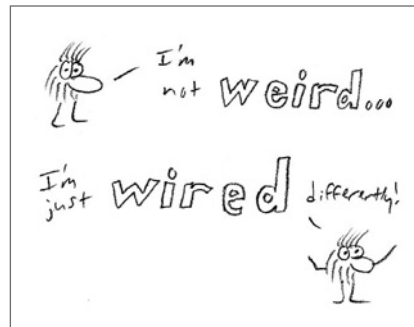
By Carol Gray and Abbie Leigh White
2002
Published by Jessica Kingsley
£12.95
ISBN 9781853029509

Our expert panelist, Carol Gray, is also the author of this book, which contains over 150 examples of Social Stories. The stories can be adapted and personalized to meet the specific skill or concept you are aiming to address. The book includes guidelines on how to write your own social story™ as well as how these should be introduced to your child.

This is an excellent reference book with cute illustrations which can be photocopied and coloured in. After reading through many of the examples in the book from how to brush your teeth to going shopping, you will feel more confident in writing your own social story which meets the needs of your own child.

Tori Houghton

BOOK **Dude, I'm an Aspie!** By Matt Friedman
2009 Published by lulu.com £4.09 (or free to download)



This quirky and brilliant book was written by an adult who was diagnosed with Asperger's in adulthood as a way of explaining his condition to important people in his life. The author cleverly and humorously uses his special interest of doodling to describe Asperger's. It's simple and effective, the sort of book for anyone to read - and everyone should. Its informative content includes several memorable captions. My favourite: "I'm not WEIRD, just WIRED differently."

Tori Houghton



BOOK

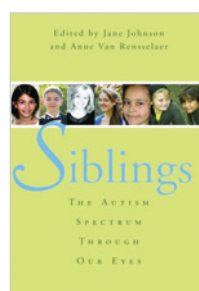
The Incredible 5-Point Scale

By Kari Dunn Buron and Mitzi Curtis
2008
Published by the National Autistic Society
£10.50
ISBN 9781905722501
NAS code 823

Sometimes, the simplest ideas are the best. Two teachers in America discovered that the easiest way of getting autistic children to recognise and regulate their behaviour was by using a five-point scale. In doing so, they were able to morph abstract-based notions into concrete social direction.

The National Autistic Society liked their book so much that they published a British version. It's easy to navigate, with explanations of how scales can be used in a variety of situations, such as controlling voice volume, anxiety or anger. Each scale has a case study explaining its background, supporting notes and Social Stories™, sometimes showing the emotion from the student's perspective as teacher and pupil worked together to produce the scale. A flexible method for ages seven to 13 and most abilities.

Debby Elley



BOOK

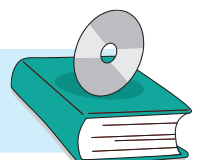
Siblings: The Autism Spectrum Through Our Eyes

Edited by Jane Johnson and Anne Van Rensselaer
2010
Published by Jessica Kingsley
£8.99
ISBN 9781849058292

Written by siblings themselves, this is an opportunity to read stories, share feelings and listen to messages of advice from people who really do understand. The siblings range from nine to 41 years old and have brothers and sisters right across the spectrum. It's a great opportunity for siblings to relate to other people and a chance for parents to hear what other children think and feel when living with a brother or sister with autism.

Tori Houghton

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



The Last Word



What I Did in My Holidays (my back to work essay)

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

Whilst Tori spent the summer in the African sun, witnessing beautiful sunsets, spotting wild animals and educating parents on speech therapy techniques for autism, I was in a caravan in Keswick.

Yes, that's right, whilst my co-editor was gazing out onto a dusty and exotic horizon, I was wondering which sort of delusion had caused me to suppose that Cumbria, not exactly renowned for its searing temperatures, would bestow anything on us other than drizzle for an entire week. Actually it wasn't delusion at all, it was a kind friend who'd given us a free holiday. So to be fair, given current finances, even if typhoons had been forecast, I'd have jumped at it.

But there was no mistaking the delusion that led us to believe that a Lakeside steamer across Windermere would be a fun idea, despite the fact that on this particular day the battleship grey of the lake was barely distinguishable from the doom-laden hue of the sky above it.

It was down to us and some enthusiastic Japanese tourists to put a brave face on it. Alec, being a sensory seeker, DID put a brave face on it. Rain! Wind! Input, input, input - gimme that weather! He stayed with his father on deck, raindrops hurling at their faces and wind billowing through their waterproofs. Bobby and I opted for the warm cabin below, with me pointing out the odd interesting seagull and Bobby asking if he could find Paloma Faith on my iPod Shuffle.

Now all this might seem rather negative. But actually, this is one of the best holidays we've had with the twins. I know what you're thinking: Where did they go last time - Iraq? The thing is, this was the first time we'd actually put our own needs alongside those of the twins instead of firmly beneath them. Their autism had caused me to be so fixed on what they could and could not achieve or enjoy, that I'd stayed with the tried and trusted. The farms, the train rides, the soft play areas...

I finally thought, if I see another ruddy goat I'll scream.

So, we went swimming (because they like it) and then we went to the James Bond museum (because I have a thing for 007). We went on a steam train (because they like it) and we went to an aquarium (because we all like it). Finally, Gavin suggested that we took a ride in a rowing boat. Amazingly, it was without incident.

On the final day, we decided on the piece de resistance - climbing a fell. This would achieve a personal best in the doing-everything-that-we'd-normally-do-but-with-autistic-kids stakes. It was getting to be quite addictive, this *enjoying* ourselves lark.

The path was rocky but straightforward. Bobby was unconvinced. He dawdled, dragged his feet and generally sulked in true Kevin-the-teenager style (he's six) until finally I gave him a piggy-back. Alec, meanwhile, who has balance difficulties due to a brain injury and is a lot more unstable on his feet, was adopting his usual *yeah why not?* attitude. He seemed to enjoy the challenge. When he too got tired, Gavin carried him on his shoulders. Finally, breathless and triumphant, we made it to the top. The view of Windermere (in the sun!) was fabulous. To us, it was made more stunning given the fact that we hadn't done this - what we wanted to do - in years.

Bobby lay down on the heather, apparently exhausted from the exertion of sitting on my shoulders for half an hour. He seemed unimpressed with the gorgeous view, but made it downhill by himself with absolutely no hesitation after being promised an ice-cream from the van at the bottom. If there had been a Mr Whippy at the top of Everest, I think he could have made it.

Alec, meanwhile, looked rather chuffed with himself. If he could talk, he probably would have said: "To be honest mum, I never much liked goats anyway."

With apologies to our Cumbrian readers. Cumbria is really really beautiful, honest...even in the rain.



Cygnets 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.

CYGNETS' 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 Cygnets Central: 0845 070 4170

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



Providing specialist babysitting and befriending across Manchester and Cheshire

Tel: 07942815845

Web: www.timebabysitting.com



George Fanton
aged 4

Celebrity Spotlight



Brandon Vaughan
aged 6

Diagnosis: Autism/speech and language disorder.

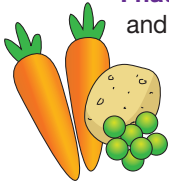
School: Warrender School in Greater London (mainstream).

Best habits: Cuddling, climbing and making people laugh.

I love: Nursery school, being outdoors, animals and my big brother and sister!

I hate: Queuing, eating vegetables and not getting my own way!

If I were Prime Minister: I would improve clubs and facilities for children with special needs and supply more paid time off work for parents to spend with their disabled children.



Song that best describes me: *Sweet Like Chocolate* by Shanks & Bigfoot.

Ambition: To be able to cope on my own.

Diagnosis: Autism.

Where I live: Manchester.

My family: I live with my mum, dad and dog and rabbit.

Best habit: I am a genius on a computer game.

Worst habit: I run...everywhere non-stop.

I love: SpongeBob, and Mario.

I hate: The rain, singing, and having my hair cut.

My personality: Jumpy, bumpy, funny, clever, fun fun fun fun. But the most wonderful thing about me is...I'm the only one!



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

P.S.

Sensory Games

How on earth an autism teacher from Surrey found the time to design her own interactive computer software for autistic children we'll never know. But she did, and www.senassist.com is the result. Affordable games especially designed to help your child along the way with reference to the P-scale system. You Tube videos on the site let you know what you're getting in advance.

Resourceful Website

How much do we like www.autismbuddy.com since we found it? Quite a lot actually. Tonnes of specialist resources that you can use at home or at school. What's really clever is that you can either buy them, or instantly download them for a cheaper price.

Go shop!

Make it Personal


Do you get tired of explaining your child's needs again and again...and again? Making a book to cover all aspects of their needs can save hassle. The children's charity Cerebra at www.cerebra.org.uk offer to design a personal guide or passport like this free of charge. If you'd like something more sturdy, you can buy a bound Me-Book. Especially designed for people with learning difficulties and personalised, Me-Books are £19.99 from MEWE PRESS on 0207 993 5308 or e-mail richard@mewepress.co.uk

A Quiet Night Out

Hats off to Dunes Splash world at Southport which has its very own nights set aside for kids on the autism spectrum. Quiet nights run from 6.30pm-8.30pm on October 26th and November 30th. Thanks to the mum who clued us up on this. Find out more at www.splashworldsouthport.com or call 01704 537 160.

NetBuddy

And finally...a tip From a Netbuddy mum...

 "A vibrating teether helped our son stop grinding his teeth and the vibrations give good sensory feedback"

Like it? Check out more tips from other mums, and add your own, at www.netbuddy.org.uk Watch out for Netbuddy tips on Aukids' new website, coming soon!