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For Parents and Carers of Children with Autism Spectrum Conditions



Friendship Special
Four pages on what it
takes to make a buddy
– and keep one!



**A Sensory
Seeker's World**
Richie Smith shares
his sensory cravings



Class Act
Drama workshops
get to the heart of
autism



GIANT
Christmas
competition
with Golden
Bear toys



4 extra
pages for
Christmas!

Letter from the Editors

Save time with our Social Story™ Service



If you want to know what a Social Story™ is and how to write one, read Issue 15 on our archive. But here at AuKids we know that you haven't always got time and we like to pamper our readers. So, we've set up our very own Social Story™ service. For just a £5 donation to AuKids (made through our website), you can ask for a tailor-made story to suit your child's situation. It will be put together for you by one of our editors.

Just write to us at editors@aukids.co.uk with a few details about the Social Story™ you'd like (covering one situation only per story). Let us know your child's level of understanding. We'll ask you a few questions and then we'll make one especially for you.



Issue 15

Just £5 per Social Story™

Hello Again!



As you can see we had a great time celebrating our 10th anniversary with a little soiree. Photographer Dave Laslett appeared in the picture himself, so he set up his camera and his wife Fiona took our pics – and a very good job she did!

We'd like to thank all of you who voted for us in Vernon Building Society's Community Awards, which we've been shortlisted for this year. The results weren't out as we went to print, but it looks like once more we'll have a decent size grant to help us out over the next 12 months. This year's grant was put to good use, enabling us to print extra magazines for visitors to shows and for support groups. With the extra pennies in our kitty we also expanded our 10th anniversary issue and this very one you're holding. Your support is truly appreciated.

AuKids is changing T-shirt suppliers (nothing sinister, Andy Davies is moving to another job). Because of this, we have some bargain stock for you to snap up! Various colours and sizes with the slogans 'Stand Aside: I have the special powers of autism' and 'I was born with autism. The cheeky smile is all my own work'. Buy one from us for just £5 plus £3 postage and packing, just ask for details at admin@aukids.co.uk



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

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



Cover Star

James, pictured with his younger sister Yasmin, is 9 years old and as you may have guessed, loves football! He supports Manchester United and plays for Stockport Dynamos. At all other times he is often found kicking a ball about and developing his football skills!



Your bumper issue is filled with brilliant contributions from the best experts about, plus some lovely prizes to win in time for Christmas. Enjoy it!

Tori & Debby



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.

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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How can we shape the future of the autism community?



Chief Executive of Autism Together, Robin Bush

Waiting lists, a lack of support and damaged families – but hope for the future. These are some of the themes that emerged from a major survey into the views of the autism community, undertaken by charity Autism Together.

The Future 50 survey, based on over a thousand online interviews, provides a unique insight into how the autism community is feeling, how community members want to shape the future, and how they'd like to imagine a future world. The report was undertaken to mark Autism Together's fiftieth year as a charity.

The report found that 76% of respondents thought that mandatory autism awareness training for public-facing staff was the biggest priority in changing the future.

Investment in education was key, too: 57% called for increased investment in special needs education.

One respondent said:

"It saddens me to think of all the budget cuts. Schools are fighting for funding and are now getting even more restricted. Outreach support is being stopped and schools forced to pay out of their own budgets! Every child should be allowed a good inclusive education."

Others surveyed thought that sufficient local authority funding (55%), extra support to help loved ones know how to make safe and happy friendships (53%) and support for properly funded respite care (45%) were also important when looking at how we can shape the future.

Surprisingly, only 22% of respondents thought

research into the causes of autism should be a strong future priority.

The report also found that 90% of respondents felt that autism awareness has increased in the last few years, and 67% felt that understanding of the condition was also improving. However, people still feel that there is a long way to go.

One respondent said: "The general public seem to have set ideas about what ASD people behave like and they pigeon-hole everyone. I can't believe how judgemental people are still."

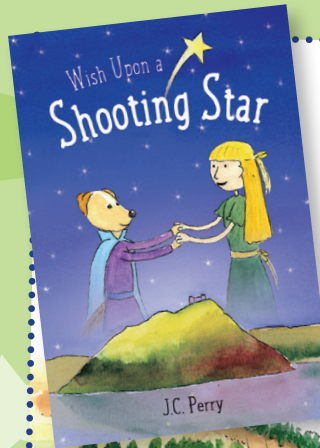
As well as looking at the community in today's society, the survey also asked respondents to get creative and suggest how they feel autism will be viewed in 50 years' time.

One respondent said: "I sometimes see autism as a new form of human evolution! A world dominated by people who focus on tasks, only take what they need, are honest, are intelligent and retain information on an astounding scale!"

Robin Bush, CEO of Autism Together, said: "Our job at Autism Together is to be there for families but we accept that what we can do is just the tip of the iceberg. The struggles we're hearing about are happening behind closed doors. Too often, autism is a hidden disability and I hope we can start to bring it out into the open."

"But at the same time, we ought to take heart. Despite everything, our friends in the autism community are incredibly resilient and are looking to the future with amazing positivity."

To view the full report visit: www.autismtogether.co.uk/future-50-survey



AuKids Designer Launches Kids' Book

AuKids animator and graphic designer Jo Perry has written and illustrated her own children's book available for general readership. *Wish Upon a Shooting Star* tells the charming tale of a very special dog and a young girl whose kindness to him is rewarded. You can buy the book for £4.99 from Amazon.co.uk



Dear AuKids

I just wanted to let you know that we took our autistic son Christopher (8) and his two brothers Daniel and Harry to Blackpool Zoo's junior Zoo Keeper Experience this week. I spoke with the keeper named Craig prior to the experience and explained Christopher has autism and is very quiet and shy and needs a lot of encouragement in unfamiliar situations and with unfamiliar people to engage. What a lovely man, so gentle and patient.

We had 1:1 with sea lions, tortoise and even hand feeding giraffes. Christopher wore a lovely blue vest with Animal Experience printed on the back and cleaned out the reindeers and another animals.

The lady on reception was so lovely and Khalid who works with the sea lions was wonderful too, encouraging the boys to touch Gina (the sea lion). Ian the manager gave Christopher an official Blackpool T-shirt which he was over the moon with and now doesn't want to take off!

Finally, Craig the zoo keeper who led the experience was so wonderful and Christopher really responded to him and even gave him a hug when it was time to go.

Highly recommended. It was expensive but well worth the money, an experience all of the boys enjoyed and one I don't think Christopher will ever forget.

Love Julie Kirby. Xxx



COMING OUT OF HIS SHELL: Christopher, Craig and Darwin the Tortoise.

Our Archive Oops!

The eagle-eyed among you will have noticed a tiny mistake in our archive last issue. Under the 'Sensory' category is the sentence 'Why does she do it and what should I do about it?' we didn't really expect you to guess what she does...it should read 'My daughter constantly mouths and chews everything. Why does she do it and what should I do about it?' - Issue 13.



Headspace

Apple Store
www.headspace.com
Learn to meditate in just a few minutes a day
Basics for free
Subscription - £5.99 per month or £71.88 a year

Headspace is an app that helps people with busy minds get space in them with just a short meditation.

Headspace is for all kids and adults. You can choose to do all kinds of meditations, from the basics, to stress, to anxiety, to the advanced meditations. There are even short S.O.S. meditations for when you get stressed or frustrated, and there are meditations for sleep. Other examples are preparation for meetings, exams, etc.

Meditations can range from 3 to 60 minutes depending on the meditation and your choice. I enjoy the ten minute ones, because they give me just enough time to chill out.

When I do this app daily, I feel more relaxed and have more space in my mind when things are getting tense. My thoughts feel less rushed and I'm able to get to sleep.

With a colourful, visual menu and simple meditations for any time, this app is great for both autistic kids and adults, for busy minds.

Bobby Elley, age 14, who has autism.

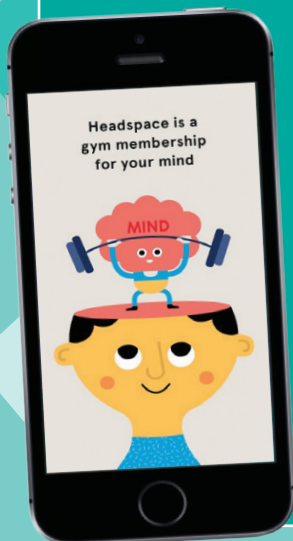
AuKids Loves Headspace!

Headspace is particularly good for helping to settle anxiety in children and has three kids' sections for ages five and under, ages 6-8 and 9-12.

We're giving away TWO annual subscriptions, worth £71.88! To be in with a chance of winning, go to www.headspace.com and answer this question:

Q. What's the name of the former monk who gives expert guidance on Headspace?

Find the answer on the Headspace website and send it to competitions@aukids.co.uk no later than November 30th 2018. Winners will be chosen at random after the closing date. No cash alternative. **Good luck!**



Reviews & Prizes



BOOK
Hall of Mirrors - Shards Of Clarity: Autism, neuroscience and finding a sense of self

By Phoebe Caldwell
Published by Pavillion Publishing and Media
£15.95 • ISBN 9781911028772

Phoebe Caldwell, who regular readers will know, set herself the ambitious aim of marrying the findings from neurobiological research, with approaches being used in care as well as what autistic people themselves are telling us. She is – sadly – still in the minority of non-autistic authors to give autistic voices the prominence they deserve.

Her own decades of experience with autism combined with her eclectic and comprehensive research of the science, make her the perfect guide for this whistle-stop tour of our current knowledge. She skilfully weaves together some of the latest findings and testimonies from a staggeringly wide range of fields and experiences; on top of many autistic autobiographies she draws heavily from the account of a neuro-anatomist who

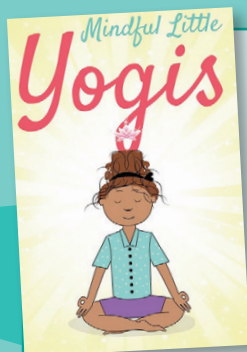
suffered a severe stroke and was able to describe - from both an 'inside-out' and a scientist's 'outside-in' view - the process of failure in the left brain.

At the beginning of the excellent practical section on Responsive Communication, she warns that "there is a real danger our approaches are out of date"; here is a simple way to get right up-to-speed. A particular highlight is the examples of how she finds ways of communicating with people in ways that make sense to them.

I have a reasonable tolerance and competence for technical discussions of scientific issues, but at times was at my limit. To truly live up to its stated aim of being accessible to lay readers, more explanation of some terminology and concepts would have helped.

Whilst this isn't exactly light reading, the reader is well rewarded for their effort with a fascinating journey that leads to a deeper understanding of the human mind, the lived experience of autistic people and how to help them exist more easily in a world not designed for them.

Mark Haworth, Staff Writer and Time Specialist Support Worker.



BOOK
Mindful Little Yogis

By Nicola Harvey
Published by Singing Dragon, an imprint of Jessica Kingsley Publishers
£14.99
ISBN 9781848194045

Author Nicola Harvey is a special needs teacher, therapist and Children's Yoga Mindfulness Practitioner.

Firstly, this isn't a book on teaching yoga to children. It includes some yoga games, but its main focus is mindfulness and what I liked was how easy it is to navigate. This is such a well-constructed little guide, taking the reader through why the approach is helpful to children with autism in a succinct way before moving onto numerous useful mindfulness exercises, easy to dip in and out of.

The approaches are mainly divided between the two key chapters focusing on breathing and self-regulation and flow. They incorporate lots of different activities, both physical and mental, and the author is highly realistic in her approach. There is nothing here that couldn't be done at home, but this book will be equally useful in the classroom.

Each breathing exercise (and there are tonnes!) starts with instructions, followed by bullet points to explain benefits and developmental skills and some extra tips to finish.

The activities are designed for a great variety of special needs and any age group; you could use this guide equally well for both verbal and non-verbal children – the breathing exercises incorporating bubbles and mirrors are particularly useful for non-verbal kids.

A valuable addition to any parent's toolkit of calming resources and I'd highly recommend this for schools, too, which could make good use of the music therapy and Lego™ ideas. I look forward to dipping into it as a reference and I value its non-preachy, highly practical tone.

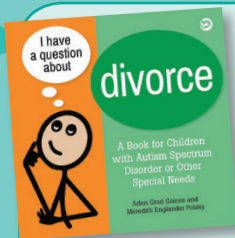
By Debby Elley

WIN

We have two copies of Mindful Little Yogis to give away. Simply tell us where we have hidden the Lotus flower in this magazine! Email competitions@aukids.co.uk no later than November 30th with your answer, or write to AuKids, PO Box 259, Cheadle Cheshire SK8 9BE. Winners will be chosen at random after the closing date. Good luck!

Find the lotus flower





BOOK
I Have a Question about Divorce – A
 book for Children with Autism Spectrum
 Disorder or Other Special Needs
 By Arlen Grad Gaines and Meredith Englander Polsky
 Published by Jessica Kingsley Publishers
 £9.99 • ISBN 9781785927874

The two authors are from Maryland, USA and both have a wealth of experience in the US social care system, having supported families and SEN children around the difficult subjects of grief and loss. Nevertheless, British readers should bear in mind that because of this there are some Americanisms in this book, with cultural references that aren't universally appropriate.

It's written using small amounts of text and plenty of colourful illustrations. It also uses 'SymbolStix' which are attractive to all children but particularly aimed at visual thinkers; they are stick figures with clear, obvious facial expressions to convey feelings and emotions in an easy to understand manner. It is designed as a tool for parents/teachers/carers to read with a special needs child, but could equally well be used for all children.

The book is written in the first person, by a gender-neutral 'kid' who is introduced on the first few pages, and then goes on to ask questions and attempts to answer them. It is made obvious that not all questions have answers, or even answers that may be liked.

There are three parts to the book, the first is the complete story, then there is a more condensed version for more visual thinkers and as a recap for more independent readers. The final section comprises suggestions for parents and caregivers for getting the most out of the book and how to inform in a non-judgemental way.

This is a practical read with simple language that will hopefully dispel some of the fears surrounding a sensitive and difficult subject.

Carey Hulme, Families
 Manager, Cheshire Autism
 Practical Support Ltd.



BOOK
MANNERS MATTER!

By Veronica Zysk. Introduction
 by Temple Grandin
 Published by Future Horizons
 £12.50 • ISBN 9781941765593

Temple Grandin is the world's most famous autistic adult. She was the first person to fully articulate in published form what it felt like to be autistic and her early best-seller *Thinking in Pictures* marked a breakthrough in our understanding of autism.

These days, among Temple's many contributions to the field of autism, she collaborates on books for children. In my view, some of these collaborations have been more successful than others, but *Manners Matter!* is a good little book. This simple guide is written by author Veronica Zysk but told from Temple's viewpoint. It explains to young readers

how she learnt manners when growing up, which manners are essential and why they matter. With large, friendly cartoons on each facing page, it's an easy read for any child from about the age of 7.

As usual with books printed in Canada or the US, there are American cultural references to jump over for a British audience – namely different terms for school. But it's a good reference and I particularly liked the section in the back written for parents, which says: 'Toss aside even the slightest notion that their ASD gives them (your child) some sort of social 'pass' or that others will make allowances for their unsocial behaviours or lack of manners. That's just not the reality of everyday life, especially as they grow up and peers become less forgiving and adults expect them to 'know better by now'.

The 20 positive tips on teaching manners at the back of the book are also extremely well done.

By Debby Elley

Have Yourself a Very Chewy Christmas!

Chewigem sells safe, chewable aids in the form of discreet, stylish jewellery and has had years of experience in designing and adapting aids for all ages and needs. At AuKids we are long-time fans of Chewigem's colourful and robust products.

Finding the right product is just the tip of the iceberg when it comes to sensory needs, though. That's why the company has developed a new **Membership Service** in which sensory seekers can come together and share advice, experiences and support. For a monthly subscription, members receive access to exclusive information and content, weekly podcasts and an invitation to a private Facebook page to exchange tips and advice.

As well as those benefits, membership entitles Chewigem customers to discounts with over 3,000 big brand partners. You can save money at supermarkets, in restaurants and even on days out.

Choose from three types of subscription

- Member** £7.95 a month with access to all of the above
- Prime** £13.95 a month includes access to all of the above plus ONE Chewigem monthly credit to be redeemed for a Chewigem product of your choice.
- Platinum** £19.95 a month includes access to all of the above plus TWO Chewigem monthly credits to be redeemed for two Chewigem Products of your choice.

WIN a Discovery Box for Christmas Worth £39.95!



To celebrate the launch of its Membership Service, Chewigem is giving Aukids readers the chance to win a Chewigem Discovery Box filled with products (perfect for popping under the tree) PLUS one month's free membership thrown in!

The discovery boxes are a great way of trying lots of different types of Chewigems for a reduced price. Each box contains 5 or 6 products of varying textures and durability, a chewing diary to help monitor your chewing plus access to Chewigem's 30-day programme to help you get to grips with your new Chewigems. There's 6 different boxes to choose from with different themes for all ages.

QUESTION: What's the nickname of the team of Chewigem Ambassadors who test and review their products? Find the answer at www.chewigem.co.uk/about Send your answer, with your name and address, to competitions@aukids.co.uk with **CHEWIGEM** in the subject header. Or write to AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE. One winner will be chosen at random after the closing date of November 30th 2018.

Please note, the prize-winner's postal details will be forwarded to Chewigem so that they can send you your discovery box. By entering you agree to this. Entrants details are not forwarded to any other third parties.

Good luck and Merry Christmas from Chewigem and AuKids!





“

My son is a friendly, outgoing and bright little guy. However, he struggles to retain friendships as he can get overwhelming for a person he grows to like. He can also get jealous if they decide to play with other children. Sadly, this has resulted in friendships being lost. Have you any advice to help manage his (and our) approach to making new friends? ”



N Azlin Sha / Shutterstock.com



Jennifer O'Toole

Among Jennifer O'Toole's many books are some best-sellers for kids on the autism spectrum, including *The Asperkid's (Secret) Book of Social Rules* and *Sisterhood of the Spectrum: An Asperger Chick's Guide to Life*. Jennifer has Asperger's herself and takes an inside perspective on this question.

Here's some not-so-breaking news: making new friends is a daunting experience for lots of people on the 'human' spectrum. The thing that a lot of folks seem to misunderstand, though, is that for a lot of us, the hard part about friendship is not actually making friends but maintaining them.

Dr Tony Attwood noticed that when asked what makes a good friend, people on the autism spectrum usually answer with negatives. In other words, we say what a good friend doesn't do,

rather than what he or she does do.

Tony's guess is that we've had a whole lot of bad experiences with so-called "friends," so we know what they're not supposed to do. Unfortunately, we haven't had enough good experiences to give a solid idea of what friends are supposed to do. Makes sense to me.

In fact, I'd add that many positive answers would also be reactions to our negative experiences, such as, "she responds to your texts" (because we've been ignored or shut out) or "she invites you to parties" (versus being left to hear about the fun we weren't invited to share).

Unfortunately, we haven't had enough good experiences to give us a solid idea of what friends are supposed to do. We know we want friends; often, though, we don't really know how to choose good ones, or even that choice exists for us.

When you are lonely, feel rejected or afraid, the want of companionship can feel bottomless. Since we can't recognize them — we continue to accept impersonators. Even the most adept autistic person is not as adept at social nuance as her neurotypical peers.

We expect the rest of the world to be the kind of friends we would be in return. We think, naively, that other people's intentions are as pure as our own. We are oblivious to hidden agendas or manipulation. It is

our biggest weakness — we can't see another's perspective, so we cannot imagine they would want to hurt us, when all we want is to be friends. And over and over, we are broken-hearted when those our false friends show their true colours.

The secret is this: we don't make friends. We make friendships. We don't build people. We build relationships — by being friendly, noticing friendly people, and taking time enough to get to know one another (the slower the better). So let's take a second to make sure we all really do understand what we should expect from a friend...and what we have to deliver in order to be a friend, too.

A friend:

- calls or texts you about the same amount as you call or text her
- returns your calls
- tags you on social media/ responds to your tags/ comments
- keeps secrets
- shares secrets
- smiles when he sees you
- likes some of the same things you do (but likes some things you don't, too)
- shares some of the same opinions
- invites you to spend time with them
- waits for you
- introduces you to other friends

- saves you a seat
- stands up for you (even if you're not there)
- stops you if you put yourself down
- listens
- compliments you sincerely
- sees talents in you that you hadn't noticed
- knows your faults and accepts them
- tells you the truth
- says he/she is sorry and means it
- accepts your apology
- laughs with you, not at you
- doesn't pressure you to do things you don't want to
- tells someone if you are in danger (yes, even secrets)
- will not always include you in everything he or she does
- means well, even when s/he makes a mistake
- likes you for exactly who you are

That's quite a list. Which is why it shouldn't surprise you to learn that in your entire lifetime, you may only make a handful or two of good friends. It is the quality of your friends, not the quantity of them, that makes all the difference.

Even the best of friends mess up. That's one of the hardest things for people on the spectrum to remember: people (like everything else) aren't all or nothing. Even among the closest friends, nobody likes everything about the other person. No friendship

is perfect because no person is perfect. Everyone has flaws. Everyone makes honest mistakes.

Your choice to make is how willing are you to tolerate a particular flaw? One friend may be a bit of a grump. Another might be awfully forgetful. How important are those things when compared with their strengths? That's a personal decision without a real right or wrong.

The ingredients of a trusted friend

1 It's A Two-Way Street

friendships are based on respect for one another and an equal give-and-take of attention from both people

2 Kindness: friends like one another and try to make each other feel happy

3 Perspective: friends ask questions about each others' lives, feelings, and ideas, in order to understand each other's perspectives

4 No One Loses: true friends can disagree, argue, get mad, and solve problems together; staying friends is more important than proving who is right and wrong

5 Things in Common: friends aren't exactly alike, but they usually have a lot in common (interests, activities)

6 Slow Sharing: over time, friends very gradually share ideas, wishes, and feelings that they don't tell others

Above All:

A worthwhile friend makes you feel good about who you are.

Why should you bother making friends, with all the effort it takes? I'm not going to lie to you - it is tough, and it does take effort. But do try. Life is better when you can choose when (not if) you'd like to be alone and when you'd like company.

Having the option to share your life with other people makes it richer. It makes happy days happier and makes heartbreak easier to handle. Learning to see others' perspectives may spark ideas you'd never have had otherwise and inspire you to discover talents you never realized were yours.

Where and How?

Start by remembering your goal: to discover real friends. The focus is quality, not quantity (one or two good friends are way better than a whole crowd of unreliable ones).

You already are exactly who you are supposed to be. Getting yourself nervous about what you should say and what you shouldn't do is going to make you try too hard. It'll come off weird and uncomfortable. Be you - don't fake an interest or say you know all about something you don't. Keep it real.

Who to choose?

The most important thing you can do (and the one where we often have the worst track record) is CHOOSE the right people to approach as possible friends. You want the right person, not just the obvious person.

For example, at school, kids in the centre of the crowd may seem the most attractive. But they're pretty busy keeping themselves and the rest of the room entertained. Eliminate the obvious choices - the people everyone else picked.

Choose to approach people who, like you, will be real value as a friend and work hard to be good friends in return.

When you want to make a new friend:

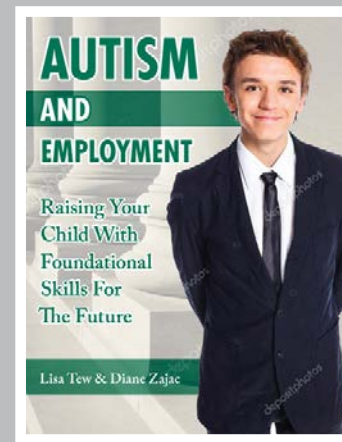
- Smile
- Try a little of everything: doing more than one activity gets you around lots of different social circles.
- Notice: Look at what someone is reading, wearing (T-shirt graphics), or doing for clues about their interests.
- Ask about their interests.
- Remember: have you spoken with this person before? What do you remember learning about what he likes that you could discuss?
- Talk to someone else who is on his or her own. Or, if there is a small group talking about a subject that interests you, walk over to the edge of the group and listen for a while before speaking.
- Give compliments.
- Take turns! Listen twice as much as you talk.
- Look for chances to talk about things other than the work if you are put in a small group or with a partner in school.
- Join a club or activity.

Whatever you decide to try, the most important tip is to get started. Don't get in the way of your own happiness. A journey of a thousand miles begins with a single step. A friendship of one hundred years begins with a simple, "hello."

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autism
a hands on approach

Tuesday 13th
November 2018

Stepping Hill
Hospital,
Stockport

The 15th Annual National Conference organised by Professionals & Parents in Partnership

Just some of the Speakers
and topics you can hear...

Gina Davies – empowering us with excellent behavioural advice

Charlotte Moore – parent, journalist and author

Justin Price – 'Better Sex and Relationship Education in Schools with Autistic Pupils'

Peter Vermeulen – 'Autism and Happiness'

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Further details:

Tanya Farley – 07966 399709
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Do you have a question for *Ask the Experts?*
Email us at editors@aukids.co.uk



Debby Elley

Parent, author of *15 Things they Forgot to Tell You About Autism* and AuKids co-editor

Unfortunately, only the best mainstream schools recognise that their autistic pupils need to be educated separately in social skills. So it falls to parents to explain some quite complex social skills, things that you may not have even considered yourself until now.

Yet social skills are equally – if not more – important than academic ones. I've known a number of high achievers in my time who couldn't cut it in the real world because of lack of interpersonal prowess. So this is worth your time and energy.

Before you have the conversation, get it clear in your own mind what it is you need to explain and how you're going to explain it in a way that your son or daughter will understand.

This is difficult stuff, and it's quite threatening to hear that your way of thinking is different to most other people's, so be gentle and slow with your information. Check for understanding along the way and ask if they want you to explain it a different way.

Try not to bombard all at once – keep it simple and revisit it. My son is quite good at saying 'I'm tired now, I've taken in enough,' but some may just switch off. When that happens, choose another time to come back to it. Friendships is a topic too big to be covered in one night.

Making Friends

Friendships incorporate a multitude of subtle signals. To avoid having to interpret them all, I use some 'rules of thumb'.

Firstly, I explain to my son that just the same as he gets overwhelmed by noise in a busy classroom, friends can become overwhelmed by too much attention or demands on their time.

The second thing I explain is that friends will hardly ever tell you when your attention is too much for them, because they don't want to hurt your feelings.

That's a hard lesson for an autistic child to learn, but knowing that people won't be direct is quite important.

I then talk about the differences between people; that one person won't mind you being around them or texting them a lot, but another will mind very much.

The question is, how do we know what to do when everyone is so different?

One 'rule of thumb' is to match the other person's friendship style.

This is when I get the weighing scales out from the kitchen. We put a weight on one side, showing that your friend has texted you or asked you to play, and then a

weight on the other side, showing that you have contacted them back.

Then we show what happens when one person makes all the effort – the friendship becomes unbalanced. The trouble with an unbalanced friendship is it is unlikely to last, as it is unequal.



That suggests that your child may be overwhelming their friend, or they may get upset or bored of making all the effort. Even if we don't mind making all the effort, people who won't balance the scales with their effort aren't real friends. Silence is a signal and should be interpreted as such.

When a friendship starts but doesn't last, it's usually because it's unbalanced.

Using physical examples like the scales really helps explain these difficult abstract concepts.

I then start collecting the salt, pepper, Ketchup and anything else to hand and I use them as puppets! I explain my friends' different styles, how I match their styles and how they've learnt to match mine to keep friendships in balance. The friends who overwhelmed me haven't lasted, but those who learnt I need a little space and wait for my response have. On the other hand, the friends who made no effort at all whilst I put all my time on one

side of the scales haven't lasted either.

If this is all too much, just start with the concept of the scales and turn-taking.

We don't want autistic adults to be the only ones making a huge effort socially, to be walked over by their peers. We want them to be treated with dignity and respect and in order for this to happen, they need to learn the rules of balance as children. A friend who makes no effort is no friend at all, and shouldn't be treated as one.

Keeping Friends

For some kids, other people can become just another 'special interest' and it's hard to learn that they have needs and motivations of their own.

Autistic kids often find talking about their own interests far easier than processing new information from other people, which is why they aren't so great at listening and can even come across as bossy. But giving them certain things to listen for can work – like making it a 'mission' to find out the three things that their friend is most interested in.

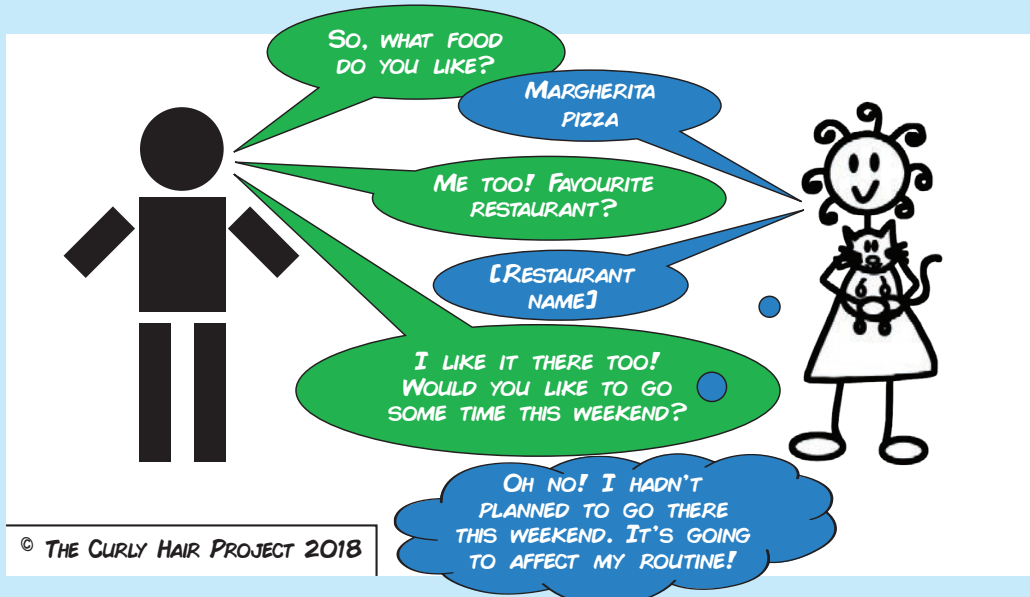
Realising that your own interests aren't the same as everyone else's can be key for autistic kids. Don't assume that they know this already – they don't! Teaching them to ask questions and wait to listen for the answers is important.

One nice way of explaining it is to say that you have two ears and only one mouth, and that's because you need to listen twice as much as you speak.

Autistic people learn through their eyes, not their ears, so this is hard for them. It can take the pressure off to explain that they don't need to remember every bit of information they're given or even understand everything – just being interested and listening is enough.

I'd also recommend that the focus when he meets up with a friend isn't on 'playing together' but on 'doing together'. This gives both friends something to concentrate on other than social interaction.

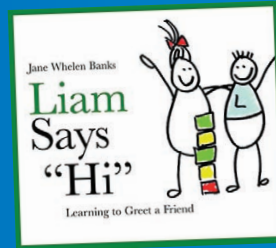
FINDING A BALANCE: Friends have to learn how to understand one another in order to achieve the right balance of demands.



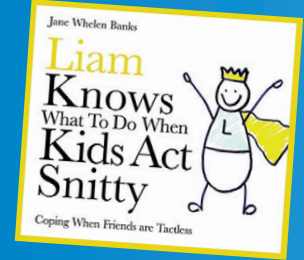
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WIN WITH AUKIDS!

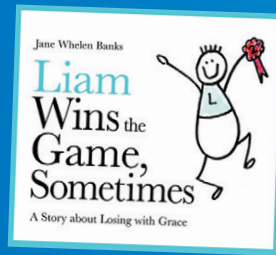
AuKids LOVES this new series on friendships by Jane Whelen Banks. The cartoons are adorable and funny; the advice simple without being patronising. We have **FOUR** books in the Liam series, published by Jessica Kingsley Publishers, up for grabs.



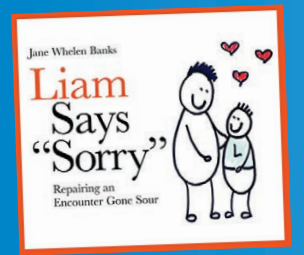
Liam Says "Hi" - Learning to Greet a Friend



Liam Knows What to Do When Kids Act Snitty - Coping When Friends are Tactless



Liam Wins the Game, Sometimes - A Story about Losing with Grace



Liam Says "Sorry" - Repairing an Encounter Gone Sour

To be in with a chance of winning all four, worth £6.99 each, simply write to us at competitions@aukids.co.uk no later than November 30th 2018 with LIAM in the subject header. You can also send a postcard to AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE. Don't forget to include your address.

Please note: the winner's name and address will be forwarded to the publisher so that they can send you your prize.

MORE INSPIRATION

- ➔ **The Asperkid's (Secret) Book of Social Rules: The Handbook of Not-So-Obvious Social Guidelines for Tweens and Teens with Asperger Syndrome** by Jennifer Cook O'Toole (Jessica Kingsley)
- ➔ **15 Things They Forgot to Tell You About Autism** by Debby Elley (Jessica Kingsley)
- ➔ **Learning About Friendship: Stories to Support Social Skills Training in Children with Asperger Syndrome and High Functioning Autism** by KI Al-Ghani (Jessica Kingsley)
- ➔ **Talk to Me: Conversation Strategies for Parents of Children on the Autism Spectrum or with Speech and Language Impairments** by Heather Jones (Jessica Kingsley)
- ➔ **The Green Zone Conversation Book** by Joel Shaul (Jessica Kingsley)
- ➔ **Conversation Series Part 3 - Issue 26** in AuKids magazine's archive

Autcraft is a version of Minecraft for autistic kids. It allows them to socialise whilst focusing on the game and with none of that confusing body language and provides a rest from the hard work of face to face contact.



REVIEW

Awkward - The Social Dos and Don'ts of Being a Young Adult, by Katie Saint and Carlos Torres, Published by Future Horizons.

Simple lists of 'dos' and 'don'ts' for a variety of social situations serve as a nudge rather than a beginner's guide for older kids who need a quick reminder of what to say and do, with discussion questions useful for groups and a little self-assessment questionnaire at the end of each example.

Reece, 14, who has autism, told AuKids: 'I think that the way the author has put a self-assessment is really helpful to the reader because that means that when they go to the next page they'd remember what was just said previously and it also gives you an understanding of the context of the page each time you read.'

'I also like the way the illustrator has drawn the comic annotations because it makes it much easier to understand especially for people with autism which are likely to read this book'.



Luke Beardon

Luke is a senior lecturer in autism at The Autism Centre, Sheffield Hallam University, as well as a speaker and author.

Luke's Perspectives on Autism blog: blogs.shu.ac.uk/autism

So, along the lines of the latter point, I wonder if in the first instance you could take the focus away from him. I would do this (if he is ok with shared reading) in the form of a story. Make one up yourself. The story could have all sorts of really useful factual information (such as what the other child is thinking as a result of a particular type of behaviour, for example) as well as positive outcomes following perhaps a slightly different approach to friendship. What a story does is take away the spotlight from the child himself - which is usually a good thing.

Once the story (or stories) have been read, then you could open the discussion about whether or not there might be any parallels with his experiences, and whether any of the strategies in the stories might be useful for him.

As well as stories about friendships, I would be sorely tempted to include a scattering of ones around being on one's own - to de-mystify it, and de-stigmatize it. We do live in a society in which there is much pressure to have lots of friends - what you don't want is the double whammy of not having a friend which is bad enough, with the extra stress of feeling bad simply because one is on one's own!

Writing about how being on your own is acceptable and can be constructive can be a refreshing message to get across to those who may find themselves on their own more often than others.

First off, it's probably worth remembering that eight years of age is pretty young for such complex issues of friendship - as time goes on he may well develop skills that will be really useful for future relationships, just in his own time. Secondly - equally importantly - you have very little influence over other kids, so try not to dwell too much on things out of your control.

Thirdly, because I like things in threes - but it's also important - whatever is used to support the young chap, it simply must not have any negative connotations. It sounds as though he's carrying the burden of pressure already by wanting friends but finding it difficult to maintain them - so he won't want any more pressure in any way, shape, or form!



Senses Working Overtime

Richie Smith was once a child bewildered by his own sensory issues. Remaining without a diagnosis of autism until the age of 33, he now uses his own experiences to help others understand sensory needs. Richie Smith's new company, Awesometistic training, aims to help parents and teachers reach a better awareness of the practical daily needs of someone with sensory processing disorder (SPD), a key aspect of autism.



When I was one and a half, I was put into care because I was suffering from abuse and neglect. I was adopted when I about 4. During that adoption, I started to take charity bags that came through the door and hide them upstairs, because they used to make a rustling noise.

Now, I didn't know why I was doing it, but I was really drawn to that rustle noise. I used to find that Sellotape and masking tape had a strong, potent smell and what I used to do was hide in the cupboard to smell these things.

As I was growing up drawn to these sensory things, I was so embarrassed, and I felt like an absolute freak. I had a secret drawer in my bedroom where I had all my sensory stuff. When I used to smell magazines with ink on them, some of the ink would rub off on my face. My parents would say 'What's that on your face, Rich?' At this point I went beetroot red. I thought: 'I can't tell anybody about this, they just won't understand'.

You know how some people with autism play with poo? Well that was me, but I didn't want to get caught so I'd use tissue paper on my hands. I started to find different ways of doing these things without getting detected. I had to become self-aware.

I could never be myself. Silk's my big thing, I like the feel of ribbon, I liked to chew it. I couldn't exactly say to my dad 'I'd like a pink ribbon because pink's my favourite colour'. I liked to bite on the silk and rub it onto my face, it just really helped me to concentrate, relax, calm...that one bit of silk could be used to control my whole world. But because I was suppressing this at school and at home, and I didn't understand it, it turned into anxiety and depression.

I started to get out of control as

a teenager. I was going through puberty and changes in the real world. I didn't even understand who I was originally, so it turned into craziness. I'd drink a lot, gamble, I even tried to take my life a few times.

When I was 21, I found my birth mother. I thought the sensory issues may have been something to do with my birth or I had attachment disorder. Unfortunately, she admitted to me that she used to cut herself, and that's when I started to do the same.

.....

“Understanding sensory needs and being able to regulate in public is so important for any child's confidence”.

.....

I didn't stay in touch with my parents, but I made sense of my adoption story and I got some answers with that. I managed to put it behind me after a lot of hard work and I have forgiven my past. But as far as my sensory issues were concerned, nobody thought outside the box to consider autism - they all thought that it was because I was neglected as a child.

Even though I came to terms with my upbringing, I still had these sensory needs, which I hid.

I met a girl 12 years ago and she changed my life. I really pushed our relationship to the maximum, but for some crazy reason she stayed. Perhaps she saw the end goal and loved me for me and not this mask of a person.

At first, I never told her that I like baby toys or to smell stuff. Eventually, I said: 'I know this sounds really stupid, but I really want these sensory rustle books you can get for young kids'. She bought me one of them. I had a dummy, the rustle book and a board with textures on.

As the years went on, we both learnt the ways best to cope with my anxiety. What we couldn't work out was my behaviour if there was a change of routine or why I had meltdowns.

But we got better at dealing with everything and I even went and got myself a degree in engineering. Funny, because I was always told I was thick and stupid. Work that one out!

Anyways, we got to the point where we had children. When my little girl was born, she used to cry very loudly and the intense and random noise really affected me. So, I went to ask for help. While I was at the doctor's, it dawned on me that I really had turned my life around. One thing I hadn't sorted was this crazy sensory overload. I decided it was time to tell him everything.

So, I did.

This is when I first heard the words 'I think you may have something called autism'. Despite a horrible 15 months waiting to get a diagnosis, I finally had answers

to my world and my sensory needs.

These days, I feel awesome and having autism is amazing and has really helped me to complete the last bits of my puzzle.

As a little boy, I learnt how to self-regulate my body with household things without anyone teaching this to me. I knew my body needed these things to help me get through the day.

It's important to understand that some sensory behaviours which are misunderstood (and do look odd) are the only way that people can manage to give themselves what they need to rest and keep them at a level where they aren't over or under-stimulated.

It's not till now that I know of products that are available for autistic children that might have stopped me feeling freakish. Understanding sensory needs and being able to regulate in public is so important for any child's confidence. Instead of wanting a dummy to chew on, I could have had a Chewigem ring that gives the same feedback (www.chewigem.co.uk).

This diagram is the best way I can explain why I did these things and why I continue to need sensory input. That line across the middle is where I try to keep myself every day.



My Tricks of the Trade!

Sensory stimulation or 'stimming' comes in all forms and it's not just for fun; it's a way to get through the day. An arrow down means that this lowers my alertness. An arrow up means it heightens it.

↓ Charity bags/ Tissue paper/ Wrapping paper

A charity bag helped me because the noise it made was so loud it really did block out everything. It was the sharpness of a noise that cut through ten other noises in a room. I used to call it the 'quick fix' because it was the best reset tool I used.



OLD FRIENDS:
This box is full of the household objects I used when I was a child.

Tissue paper and wrapping paper really helped me to concentrate – and still do. I would lie with the paper on my lap and rub it backwards and forwards. The crisp sound of my hand across the paper not only gives my ears feedback but my arm, too. For me it's the same feeling as when you see a kid rocking and clapping their hands.

Sensory stimulation or 'stimming' isn't just enjoyable for kids with autism, it's much more than that. When I am sitting with tissue paper around me, it's not a tool to relax; it actually makes me feel that I am in the room, listening, watching focusing and functioning like normal people do.

↓ Sellotape / Masking tape / Magazines

I love smells; it's like a boost in happiness when I smell things and helps block out other sensations, keeping me in that moment of peace. Of course, with children you have to watch the toxicity of the products they want to smell. I still love to smell magazines. When I am overloaded with sensory input, I need to smell and manage my day.

→ Ribbon

I chew ribbon a lot to calm me. People assume that it's just the feel of a material that gives sensory input, but actually it may be the dampness and smell after it's been chewed. (I guess neurotypical people would not think of that, because it would not be appealing to them). I now have loads of ribbon on me at all times as its ticks a lot of boxes for me. It's great to feel and rub.

↑ Chewy items

It wasn't till recently that I realised that a dummy wasn't because I had an attachment disorder. It was the need to chew - it energised me and was like a pick-me-up. Now I have a chewable necklace and I think of how much confidence that would have given me as a child. Chewing alerts me, but can also make me hyper.

↔ Ear Defenders/ Covering ears

I think ear defenders are sometimes misunderstood. I don't always wear them because there's loud noises. Sometimes I actually wear them to get rid of the quieter noises. There's actually loads of noises in a room that you may not hear, but when you CAN hear them (like me) it can be distracting.



WRAPPED UP: Richie wraps himself in paper to calm his body so that he can focus on TV and conversation at home.

Having these ear defenders actually help me to attend to what you're saying. So, where there's a lot going on in a room in terms of *all* sensory input (not just sound), I use these to keep me in the room and help me to concentrate on what I need to. At other times I do wear them because a loud noise could be enough to cause me a meltdown.

We tend to think of each sense as providing one thing to process at a time. But there can be many smells, sounds and sights to process at once. Let's say my limit is ten things going on at once. To process all of these separately it takes a lot of work. I use my ear defenders to help keep me processing somewhere between 1 and 10. If I go over that, I get burnt out and that's when I get a meltdown.

MORE SENSORY ADVICE!

Richie's sensory 'diet' is individual to him. Don't miss our January issue, when Occupational Therapist Breanne Black will be taking you through a variety of activities and products that alert the system and those that calm, so that you can tailor your child's input to suit them.



TREASURE TROVE: This box is full of the sensory products I use these days, designed for sensory input. Aren't we spoilt for choice?

Read more about Awesometistic and follow Richie's blog at www.awesometistic.co.uk

E-mail: Richard@Awesometistic.co.uk

If you book one of Richie's workshops, please mention you saw him here!

In Harmony With Autism



The Duo by Percussion Play © Robin Ashfield

How Musical Instruments Help Kids on the Spectrum



VICTORIA DOXAT is a writer and lecturer at Havant and South Downs College, with a keen interest in music therapy. She has been collaborating with Percussion Play, a leading manufacturer of outdoor musical instruments, to research the benefits of music for children with autism.

We know that no two children are the same, but there does seem to be one activity that is guaranteed to appeal to all children everywhere - music! Music never fails to engage us and even hard-to-reach children seem able to connect with and respond to music on some level.

The health benefits of playing musical instruments are well known and you will no doubt have noticed that your child seems calmer and less anxious after they've heard their favourite song being played or taken part in a music class. When musical instruments are placed within an outside space, children also experience the many health benefits of playing in the fresh air including increased levels of vitamin D, improved sleep and better mental health.

Here's some more ways in which music can help children with autism:

1 Fun for everyone

Everyone in the family can get involved in playing musical instruments no matter what their age, ability or level of mobility. Music encourages people to play together and grandparents, parents, children and even babies can enjoy making music and spending time with each other in a fun, enjoyable and relaxing way.

This gives their confidence a powerful boost and with encouragement your child can start to apply this new confidence to other areas of their lives such as work or education.

For children who are non-verbal, the ability to connect and communicate with others through music is particularly powerful. Some children find it difficult or impossible to express themselves verbally and this can be very frustrating. Playing musical instruments can help your child to overcome these frustrations by teaching them to express themselves without fear.

2 Music is good for your health

Playing musical instruments has been proven to reduce anxiety and depression, lower blood pressure, decrease heart rate and improve our ability to fight viruses. Music therapy is now recognised as being one of the most accessible forms of therapy and is now being used in a range of settings all over the world to help people living with a range of conditions and disabilities.

3 Increases attention span

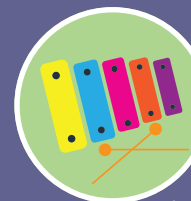
Music is a universal language and is very well suited to the needs of autistic children because playing music can capture and maintain your child's attention in a way that other activities do not. Playing musical instruments in a group requires watching, listening and copying the movements of others and when these actions are repeated over a period of days, weeks and months the concentration levels of those involved will improve.

4 Improves self-confidence

Playing musical instruments can also increase your child's self-confidence and improve their self-esteem. Creating music is empowering and teaches children that they *can* achieve.

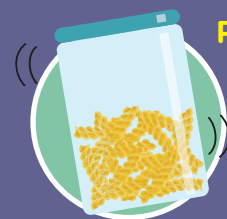


Vicky's Tips to Get You Started



GIVE ME FIVE!

Invest in a Pentatonic xylophone-pentatonic instruments have five notes that are tuned to the pentatonic scale. When your child plays with a pentatonic xylophone they can play the notes in any order and it will always sound good, so less frustration! Check out the Metallophone from New Classic Toys on Amazon for around £10.



PERCUSSIVE PASTA!

A shaker is free and so easy to make. Take a plastic bottle with a lid and fill with pasta, rice or buttons, and then Sellotape or glue the lid on. An instant way for your child to beat a rhythm. You can turn this into a craft activity by painting the bottle first or adding stickers.

5 Reduces feelings of fear and anxiety

Music therapy helps children learn how to relate to others and very young autistic children benefit from playing musical instruments because music motivates the child to follow more impulsive play patterns. Autistic children often find it difficult to act in a spontaneous way and activities which encourage impulsive play can help them to become more rounded.

The familiar sounds of the musical notes can also promote feelings of security in children who are resistant to change or who experience anxiety. Music has a soothing quality which helps to calm children during or after a meltdown and it can also help make bedtime routines or daily tasks easier when specific songs are used to accompany particular tasks.

6 Boosts brain power

You may have heard of the 'Einstein Effect' - there has been a lot of research into the effect of playing music to babies and there is some evidence that playing classical music in particular can boost brain power. Music stimulates both the left (analytical) and right (creative) hemispheres of our brain and this is why playing musical instruments is linked to improved cognitive function and increased language development.

Music is used effectively in autism therapy because playing musical instruments stimulates the autistic brain to make new connections and strengthens existing ones; resulting in improved mental health and increased cognitive ability.



OUTDOOR AMBIENCE

Take your child to an outdoor musical park. Percussion Play have installed their musical instruments in hundreds

of parks, museums, zoos, children's farms and other outdoor attractions.



JUMP TO THE BEAT

Piano mats are a cheap and easy way to get your child moving. Your child can jump, dance and roll

over the mat to play the notes. Great for children to play together. The piano mat can be rolled up and stored away when not in use. Prices start from £9.99



TUNE IN TOGETHER

Stick on the radio! Find a radio station that you and your child enjoy and have a boogie. Dancing is great exercise and releases feel-good endorphins. Encourage your child to keep to the rhythm by clapping along together. Free!

7 Better communication skills

Children with autism often find it very difficult to communicate with and to interact with others and so any activity which involves participation is to be encouraged. Introducing musical instruments can be a great way of initiating communication with others because your child has to first learn how to connect with and communicate with an instrument.

Some musical instruments, such as 'The Duo' by Percussion Play have even been specially designed to appeal to children and adults with autism and allow for close social interaction without forcing close physical proximity or requiring direct eye contact between players.

Music helps communication because music making goes beyond words and often creates powerful emotions in those who play. When these emotions are shared with others we are able to connect with each other on a deeper level and non-verbal communication is established. When children who struggle with verbal communication play musical instruments with others there is often evidence that their verbal communication improves as a result.



8 Encourages socialisation

When we play music together we develop social skills without even knowing it. Playing musical instruments helps children to participate in a socially acceptable way and reinforces desired responses such as turn-taking. Research tells us that music therapy helps children to interact positively with those around them and so it is no surprise that when autistic children are encouraged to play musical instruments with others their social skills improve, often dramatically.

9 Motor skill development and coordination

Playing outdoor musical instruments is brilliant for developing both fine and gross motor skills and encouraging physical activity and coordination. Children will run between instruments, use their whole bodies to dance or sway to the music and will use beaters to make a sound. Playing the instruments requires hand-eye coordination and some children even use the instruments as climbing frames! This means that even a short outdoor music session can result in a lot of physical benefits.



10 No wrong notes

Some musical instruments are 'pentatonic'. This means that the instrument is made up of notes that are taken from the pentatonic scale. There are five notes in the pentatonic scale and these notes always sound good together no matter which order they are played in. If your child is anxious, shy or reluctant to engage in activities, try introducing them to pentatonic instruments. It is impossible to play a 'wrong' note and the pentatonic scale has a very pleasing sound which even the most reluctant child will want to play.

Because there are no boundaries with music and no rules, there is no 'right' or 'wrong' way to access musical instruments and so your family can use music and musical instruments in a way that suits your individual needs and preferences. Playing musical instruments also assists your child to participate in socially acceptable ways and helps to reinforce desired responses.

For a child living with autism, music may well be the most effective, as well as one of the most accessible, forms of therapy available to them today and encouraging our children to play musical instruments from a young age may be one of the very best things that we can do for them.

Further Information

You can access the original findings of Victoria's research on the Percussion Play website at www.percussionplay.com. If you would like to contact Victoria, e-mail hello@victoriadoxat.com

Save for your School with Percussion Play!

AuKids has teamed up with Percussion Play to offer a 10% discount off any Percussion Play product/s ordered before 31st March 2019. Pass the code on to your child's nursery, school, or Friends of Park group! All our images feature Percussion Play instruments. Use the discount code **AUK10** at www.percussionplay.com

What to do while you're waiting...



Waiting for a Diagnosis

by Debby Elley, parent

Whilst it's true that diagnosis provides the key to funding, understanding and support at school, it isn't true that all progress needs to be put on hold until that time.

In fact, waiting for an autism diagnosis whilst a child is very young can be beneficial and even vital. Autism is diagnosed by assessing the presence (or lack of presence) of language, social communication and other traits. These develop at very different rates in young children and a judgement too early could be misleading.

Frustrating as it may seem to you when you just *know* as a parent that something isn't quite right, waiting a little can make the clinical picture much clearer to a paediatrician. This doesn't excuse over-long waits brought about by a lack of resources, but it does give a reason for a small amount of waiting whilst it is early days.

So, what can you do while you're waiting? As part of an autism assessment, you'll be asked a series of questions about your child's behaviour at home. It's a good idea to note down where you think your child's behaviour is unusual or very different from their sibling's development or that of other children in your family. When you do note something, check to see whether that behaviour is consistent or linked to a certain environment or time.

You can still read about autism even if your child hasn't yet got a diagnosis. Autism parenting strategies are simply great parenting, and as long as you're not embarking on a specific therapy programme or seeking any medication, ordinary daily strategies won't do any harm at all – so go ahead, look up some advice in AuKids!

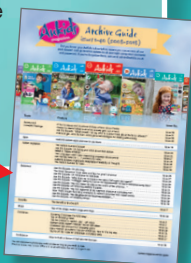
We'd advise that if you're getting information, get it from an impartial source, such as ourselves or the National Autistic Society.

If your child is struggling with the unexpected, visual timelines showing a routine in symbol form can prove very settling at school as an early intervention. Try Orkid Ideas at www.orkidideas.co.uk for some great resources.

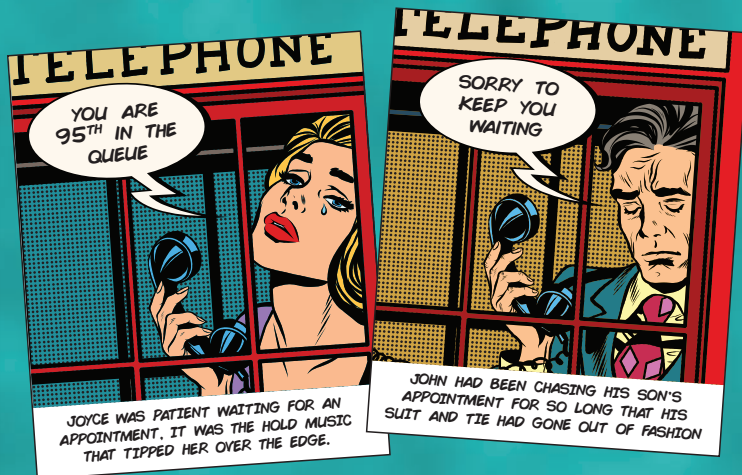
You don't have to buy an expensive computer package to get a symbol – use photographs, download images from Google or draw pictures of the activities your child likes to do. Then, if he/she struggles with understanding aspects of language, you can show them what you are about to do/where you are about to go using visual references.

Further Information

- The National Autistic Society runs EarlyBird (under five years) and EarlyBird Plus (age four-nine) - support programmes for parents and carers offering advice and guidance on strategies and approaches for dealing with young autistic children. To find your nearest centre go to www.autism.org.uk/services/community/family-support/earlybird/licensed-eb.aspx or contact training.enquiries@nas.org.uk
- *Explaining Autism* by Clare Lawrence, published by Emerald, is one of our favourite overviews.
- Use resources on the National Autistic Society's website at www.autism.org.uk On the site, you can look up your local branch too, so you'll be able to get early support from them. The site also includes an Autism Services Directory.
- Use our archive from Issue 40 to look up anything you'd like help with, and if you haven't got the archive and are a subscriber, write to editors@aukids.co.uk and we can send you a pdf.



The reality of life with an autistic child is that we spend a lot of time on waiting lists for appointments. And while we wait, we worry. We worry that we're losing precious time that could be better spent and that things will move beyond our control if nothing is done soon. It's so frustrating. Given the reality of this, though, what can be done in the meantime? Here's some advice...



Waiting for a Mental Health Therapist

by Debby Elley, parent

One thing to make clear from the outset – if your child is in danger of hurting themselves or others, you should not be waiting. Ask your paediatrician for help in getting you seen.

Many children with autism develop secondary mental health problems caused by high anxiety. As prevention is always the best cure, work with school and with any outreach services available to school to ensure stress reduction in your child's environment. If you're not sure what help is available to you, contact your local branch of the National Autistic Society, or ask the school's SENCO (Special Educational Needs Co-ordinator). Structure and routine can help considerably, as can reasonable adjustments to avoid noisy, overwhelming situations, make the day more predictable (with warnings for imminent change) and reduce pressure.

We shouldn't really have to say this, but it's worth checking to see if you have any private medical insurance covered by your workplace. If your family is covered under your agreement, you may well be able to see a mental health practitioner privately.

If you're fairly certain that your child may need medication, ensure that your first assessment is with a

psychiatrist, as they are the only ones in a CAMHS team able to medicate.

Ask for help early - assume you'll be waiting a while.

Funding is desperately needed in this area. Help change by booking an appointment at your local MP's surgery; our voices need to be heard in Parliament.

Further Information

- Young Minds is a good website for all sorts of help and has a crisis text line for young people. www.youngminds.org.uk
- The EarlyBird Healthy Minds programme is a six-session parent support programme run by the National Autistic Society to help promote good mental health in autistic children. For more information call the EarlyBird team on 01226 779218 or email: training.enquiries@nas.org.uk
- Dawn Huebner's books *What To Do When You Worry Too Much* and *What To Do When Your Temper Flares* are firm favourites of ours.
- *Breaking Free from OCD: A CBT Guide for Young People and Their Families* by Jo Derisley, Isobel Heyman, Sarah Robinson and Cynthia Turner is a rather good guide.



Waiting for a Speech and Language Therapist

by Tori Houghton, Speech and Language Therapist

Perhaps one of the first signs that your child is not developing in a typical way is a delay in their communication skills. A difficulty with understanding language and expressing themselves may lead to a lot of frustration. Children who do go on to have a diagnosis of autism can have varying levels of communication difficulties – but here is some general advice on what you can try with them whilst waiting for a speech and language therapy assessment.

.....
Don't try to correct them or make them repeat it, just demonstrate the right way, e.g. if your child says "tat ditting" you say "Yes, the cat's sitting!"
.....

Children with social communication difficulties struggle to share attention, i.e. focusing on the same thing as you. This is a critical skill for learning language. They need to know what the word you are using refers to. Put some time aside to observe them. What do they like? What are they interested in? What captures their attention? Get into their world and allow them to show you, without you trying to take over. Don't worry if the toy teapot goes on their head or they bang bricks instead of building them! Instead of 'correcting' the play, use it instead as an opportunity to share attention.

Once you are looking and playing with the same thing, this is a critical time to introduce

a word. Keep it simple, start by just 'labelling' what you're looking at. Repeat.

Remember that in the early stages of language development, children need to hear a word almost 50 times before they can fully understand its meaning and are able to use it appropriately.

Use this time to 'feed' your child's language at an appropriate level. A general rule of thumb is that if a child is pre-verbal, use single words to comment on what they are doing, if they are using single words, you can increase your utterances to two words etc.

If your child is verbal but they mispronounce words and you struggle to understand them, try to listen to *what* they are saying. Let them know that it's really important to you, but that sometimes mummy/daddy doesn't hear or their ears aren't working today. Don't try to correct them or make them repeat it, just demonstrate the right way, e.g. if your child says "tat ditting" you say "Yes, the cat's sitting!" This helps them to build confidence in their own attempts.

Observe how your child communicates at home. How does he ask for a drink? How do you know if she's had enough? How do you know if he wants more of something? These are questions the speech therapist may ask you. The answer may be that you just know! You're the parent, after all. However, think about what signals your child may be giving you to indicate these needs. Try not to anticipate their needs, allow them to use these signals.

They may not be using words, but they may be giving you lots of non-verbal cues about what they want. The more you respond to these signals, the more this can develop into meaningful communication.



Final Tip

All types of appointments will benefit from good preparation. The more thoroughly you can write down your observations, the better equipped that you – and the therapist – will be to produce a suitable strategy.



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Waiting for an Occupational Therapist

by Breanne Black, occupational therapist.

An Occupational Therapist is often able to help with the development of motor skills, perceptual skills, sensory processing and activities of daily living.





Before your appointment it's a good idea to write down any concerns that you wish to discuss with the O.T.

If your main concerns are relating to sensory difficulties, make a point of observing your child's responses to touch, sound, vision, taste, smell and movement. Do they find it difficult to sit still? Are they bothered by things you may not expect to prove troublesome? Do they constantly touch things?

It may also be useful to note down situations in which you feel your child struggles or becomes overwhelmed, note the environment and what happens before and after. Some parents like to bring relevant footage on their iPad

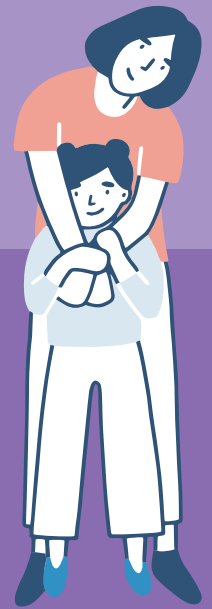
or phone regarding behaviour that they can show the O.T and that can be useful.

Further Information

- **Sensory Perceptual Issues in Autism and Asperger Syndrome** by Olga Bogdashina (JKP) 
- **Building Bridges through Sensory Integration** by Ellen Yack and Paula Aquilla (Sensory Resources) 
- **Making Sense: A Guide to Sensory Issues** by Rachel Schneider (Future Horizons) 
- **The Out-of-Sync Child** by Carol Stock Kranowitz (Perigee) 

7

Ways to Be Your Child's Learning Partner



Dr Heather MacKenzie is a Canadian speech and language pathologist* who has spent her career developing and implementing approaches for enhancing learning in children with special needs. Her focus is on translating current research into sound clinical practice. She has a special interest in children with autism and how to optimize their development. She is also the creator of SPARK**, an innovative evidence-based programme that teaches children how to manage and regulate their behaviour, thinking and emotions more effectively.

Self-regulation is the ability to control your own body, thinking, and emotions in ways appropriate to different situations. This is critically important to children's learning and their ability to become healthy, happy, independent adults.

When it comes to self-regulation in our children with autism, we have to learn to let go.

We have to allow them time and space to become more independent.

Our ultimate goal in teaching self-regulation is for children to make choices for themselves. They need to develop a sense of freedom. This means they become more autonomous....and they don't need us so much.

Carers can often find themselves taking on the executive functioning part of the brain on behalf of children with autism to help them plan. So, how do you go from hovering so disasters don't occur to giving children space to become more independent?

Find the balance between your actions and your words. Stay calm (calm adult = calm children) and show confidence in your child's ability.

The words we use are critical. Even if you're not sure your child will understand everything, at the very least they'll understand your tone of voice. When working with children with autism, we become used to telling/ordering them what to do. We also do things for them a lot. These are 'doing-to' and 'doing-for' approaches that ultimately keep children dependent on the adults around them.

There are certain times when we need to tell a child what to do, like 'Stay away from that dog!' Plus, some 'doing-for' things represent steps in the right direction. For example, when we set up visual schedules and streamline the environment, it's clearer to children what they're expected to do. Over time, we want them to organize themselves and cope with some uncertainty.

It's a good idea to move from 'doing-to' to 'doing with' our children. That means becoming a learning partner.

Becoming a learning partner is not easy to do. You have to be willing to wait, watch patiently, and let your child make mistakes. It's important to focus on the end-goal: we want children to Do-It-Yourself. We want them to plan and organize on their own, inhibit unhelpful behaviours, remember what they plan to do, check their own progress and change approaches if need be.

That's huge! But here are some beginning steps:

1 Sit back

and pretend you're in the passenger's seat and the child is the driver. Trust yourself and trust the child.

2 Use inclusive language

For example: 'Hmm...how do we do this?' It's a simple but powerful way to tell your child you're in this together and you'll be there to support them if needed.

3 Ask using suggestions...

...rather than telling them what to do. Use phrases like "How about ...?" "What do you think if we do it this way?" or "What'll happen if we do it this way?" when making suggestions.

4 Give hints and encouragement

Prompt children to think for themselves and figure things out by pointing out clues. Ask them: "Did you notice this thing over here?", "Do you think that might help you?", "What do you need to do?" or "What could you do to help yourself?"

5 Give them choices

Choices can be about what to do, how and/ or when or by giving a reason when choice

is limited. Choice is powerful. It tells a child they're important and have some say. Choices can start out really simply. For example, you decide what things need to be done but the child determines the order for completing them. You offer milk and juice and your child selects one. Remember, once children make a choice, you have to respect it...even if it's not what you had in mind.

6 Invite and value their opinions

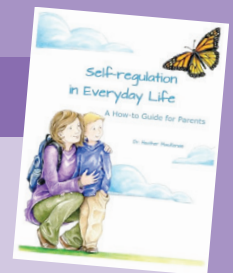
Ask about what they'd like to do, how they'd like to do it, why they don't want to do it, etc. Listen to their ideas and respond to their suggestions. Acknowledge their outlook even if you disagree.

7 Think out loud

Explain in simple terms what you're thinking and the reason you want to do things in certain ways. You may not get your way, but the youngster will learn about other ways of doing things.

EXTRA INFO

Self-regulation in Everyday Life: A How-to Guide for Parents



Self-regulation in Everyday Life is a step-by-step guide for every parent who wants to help their child be better prepared for school and for life - By Dr Heather MacKenzie - Published by Wired Fox Publications. Follow Wired Fox Publications on Facebook for more from Heather.

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Set the Stage for a Closer Connection



Jane Gurnett



Tessa Morton

ACT FOR AUTISM is a not for profit social enterprise which was set up in 2015 by Jane Gurnett and Tessa Morton, both autism mums. The founders have used 20 years of joint experience as counsellors, actors and drama teachers to give those working and living with autistic children a deeper understanding of sensory experiences and a more thoughtful approach to communicating with them.

By Jane Gurnett

When Tessa and I first teamed up to design our training, we asked ourselves what was missing from current information on autism. We agreed that although there were plenty of behaviour strategies out there, there was a lack of emphasis on our understanding of what sensory differences and environmental challenges can feel like first-hand to an autistic person.

At Act for Autism we believe that living an experience works best, so we set about creating training for parents and teachers of autistic children on that basis. Our workshops use drama to achieve a sensation

of processing overload that stays with participants long after the workshop is over.

Our mission is to help parents and teachers follow the principle of 'understanding and connection first, strategies second'. Once you've deeply understood the challenges a child faces, you are far better placed to analyse the underlying reasons for behaviour and create more effective methods for connecting, calming and communicating.

Now it gets really tricky. As the second facilitator, I ask questions like 'What did you have for breakfast?' It seems simple, but time and again we've witnessed that participants find it nearly impossible to answer a simple question when there is an overload of instructions that have to be cognitively re-ordered.

Further Information

On Act for Autism's site at www.actforautism.co.uk you can view their 10-minute Autism Voices film, in which autistic children share their experiences of school. www.bit.ly/AutismVoices

Jane Gurnett's academic article: 'How can Shakespeare's Iambic Pentameter enable inclusion of and encourage participation of autistic pupils in a Year 7 boy's mainstream classroom?' appears in Emerald Publishing's *Advances in Autism* journal.

Act for Autism runs workshops for both parents and professionals and can be hired as part of an inset day. For further information visit www.actforautism.co.uk or email info@actforautism.co.uk Prices for workshops on application.

Living the experience

Exercises which we use early in our workshops create the sort of overload (either sensory or information processing) commonly experienced by autistic people.

As Ralph-Axel Muller, a neuroscientist at San Diego University, explained: "Impairments that we see in autism seem to be partly due to different parts of the brain talking too much to each other. You need to lose connections in order to develop a fine-tuned system of brain networks, because if all parts of the brain talk to all parts of the brain, all you get is noise."

Here's an example of one of our exercises: In this game, you need two facilitators. One gives physical instructions for the participants to follow. The other asks the participants questions at the same time. Sounds simple? Not the way we do it!

Let's use Tessa and I as the facilitators to show you how it's done.

Tessa instructs the participants to jump if she says 'Clap!' and clap if she says 'Jump!'. They also have to follow the opposite of her instructions for up and down, bending their knees when Tessa says 'Up!' and putting their arms in the air when she says 'Down!'. Lastly, when Tessa orders them to 'Stop!' participants must run on the spot and when she orders them to 'Go!' they must stand still.



It is arguably a crude approximation of what it might feel like to process too much sensory information, but it has the desired effect. People at our workshops have reported anything from wanting to run away (shutdown or our instinctive 'flight' mechanism) to wanting to shout 'Stop it!' or even punch the facilitator! (meltdown or our instinctive 'fight').

As an autistic child, if 'all you get is noise', it is almost impossible to communicate your wants and to participate in activities.

During our workshops, we follow this exercise by talking about three stages to interacting with an autistic child, rather than just one. We call this the 3Cs Pathway.

**The three Cs are:
Connect-calm-communicate.**

How to Connect

Connection seems simple to achieve, but parents and teachers have an exhausting amount of daily juggling to do and are often under immense pressure. In our recent research survey, lack of time was in fact the biggest worry for parents. This feeling of pressure leads to anxiety, which can in turn negatively impact our children.

We advocate 'Clear-Time' to help you connect before you try to communicate with an autistic child.

There is a subtle difference between connection and communication. Communication demands reciprocity, the give and take of a conversation or shared activity. Given that an autistic child may be experiencing overload, asking for something back whilst they are overloaded and consequently anxious, can often result in shutdowns or meltdowns. This presents as 'challenging behaviours' or as we would rather call them, distress signals.

For **Clear-Time**, you reserve just 5-10 minutes for connecting with your child.

Clear-Time requires being alongside your child in total unison, free from distractions -



not talking to anyone else, or answering text messages.

In feedback from our workshops, some participants said that **Clear-Time** helped with de-escalating while others said it reminded them to stay calm and to give their children time for processing.

We know that sometimes it is hard to prise your child away from their device or mobile, but time spent regularly each day, ideally at the same point in the day, can also act as a bridge to implementing **calming** exercises.

This is because joint involvement exercises create less pressure to produce results, and help children to actively participate in calming strategies, rather than feeling that they are the passive recipient of a 'lesson' in calm.

It's worth noting that if your child is non-verbal or you feel you already have a good connection, calming exercises can act as a mode of connection, too.

How to Calm

- **Heartbeat Rhythm:** We have found one of the most successful strategies for calming is using 'heartbeat rhythm'. When your child is sitting next to you, beat out a resting heartbeat rhythm with your right hand on your heart or on your thigh. If your child asks why you are doing this, simply say 'I am calming myself' or 'It stops my heart going too fast'. This is showing, not telling - a demand-free demonstration.

- **Speaking Rhythm:** Use a heartbeat rhythm when you speak. Even an attempt at this, although it may not be totally accurate, will bring your body rhythm to an even, de-stressed

state. In this state, you can talk in calm, short sentences with no rising inflections. We use a rising inflection at the end of a question and if your child is overloaded, it can make them anxious. To see a demonstration of this rhythm, watch Tessa and me at www.youtube.com/watch?v=2WfLpoMcrIw

- **Heartbeat Hug:** Simply hug your child and softly tap a heartbeat on their back. As with all the exercises, some children will love this, some won't, so experiment.

- **Candle in the Wind:** Breathing exercises are fantastic for calming. Our favourite is 'blowing out the candle'. Hold your hand in front of your mouth, breath in through your nose for 4 counts, breathing right down into your stomach and then slowly breath out through your mouth, blowing on the palm of your hand as you move your hand away from your face.

When you can't feel the flow of the breath on your hand any more, bring your hand back in front of your mouth and repeat by breathing in through your nose.

TIP FOR TEACHERS AND TAs: Obviously it's not practical to make Clear-Time every day, but you can make that connection first, by taking an interest in your pupil's special interest and spending a minute at the end of the class checking in with your pupil to build a relationship before you try to implement any strategies.

I now know not to keep talking to him when he's stressed. I just sit next to him, stroke his arm and wait for him to calm or use breathing exercises to calm him and myself. I've stopped wanting to find out what's wrong and started to understand how important me just being there is.

Parent on Clear-Time

Why is heart rate important?

A British study presented at the 2012 International Meeting for Autism Research showed that young people with ASDs (with and without anxiety problems) displayed a significantly increased resting heart rate compared to controls. - Hollocks, M., Grayson, L., Howlin, P and Simonoff, E (2012) 'The Relationship Between Heart Rate and Anxiety in Autism Spectrum Disorders'.

We hope you find this article useful and thanks to Aukids for asking us to contribute.



Ideas for Clear-Time



If a child is jumping around, join in, make it a game - be present, in the moment, connected to their actions, let them lead you.

5 mins

Spend five minutes talking about their special interest or something they are interested in, then spend five minutes researching something they have mentioned so that you can build on the shared interest in tomorrow's **Clear-Time**. You may even want to create a web page together, or a scrapbook, or you and your child can later share your findings with another family member or friend.



Use the time stuck in traffic to define your time together. You could read and memorise number plates together, trying to memorise them backwards. Or, use the letters collected from the number plates to try to create words.



The Last Word

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

This Article is a Load of Rubbish - NOT!

Out of all the social skills that I've worked on with Bobby, I'd say that teaching him sarcasm has probably been one of our highlights.

Misunderstanding sarcasm puts autistic people at such a disadvantage in terms of their social interactions and is often avoided altogether in social skills training.

Saying 'autistic people don't get sarcasm' just isn't the answer, though. As I'm very fond of preaching, autistic people may not naturally understand something, but this doesn't mean that they can't learn it through being explicitly taught it and through experience and demonstrations.

Since learning about sarcasm the hard way is deeply unpleasant, I'd suggest that it's worth giving this a shot.

Firstly, it helps to understand why autistic people don't like sarcasm. It's not because they don't have a sense of humour. They tend to love jokes, puns and slapstick. Autistic people are literal thinkers, though. Words should do exactly what they say on the tin. So, when you mean exactly the opposite of what you say, it's little wonder that this is problematic.

I started by explaining to Bobby what sarcasm is and the purpose it is used for. *Sarcasm is saying exactly the opposite of what you mean in a certain kind of voice, to make a joke.* It may take a while for them to see why this might be remotely funny.

Secondly, demonstrate sarcasm. Give some easy examples. "WOW I JUST LOOOOVE HISTORY!" (when you know they don't). During our next stage, I used sarcasm in a really obvious way during our daily interactions and asked Bobby whether he thought I was serious or not. "Oh - er - was that sarcasm?" High five if he got it right.

This was a prolonged stage. Making sarcastic jokes at home and around Bobby and pointing out the sarcasm went on for quite some time.

When I could see that he'd started to recognise it, I used sarcasm but hinted at it by asking Bobby 'Was I serious, then?'

After that, I stopped giving prompts altogether. Bobby started to say: 'Wait. Was that sarcasm?' The self-satisfied beam I got when he was right was immensely rewarding.

Eventually Bobby made his first sarcastic joke, by saying he'd REALLY LOVE some vanilla ice-cream when we know that he prefers chocolate. I would have been happy enough for him simply to recognise it; this to me was the icing on the cake (or the cherry on the cornet). He'd got it, and since then he understands sarcasm.

I can't promise you that teaching sarcasm works for everyone. However, just recognising that it's a form of humour and that a certain tone of voice is used for it will protect your child from some vulnerability when their peers inevitably use it. Practising it at home in a safe environment where mistakes can be made is the ideal start.

There's no time limit to learning, so if they're not ready for it yet, try again at a later stage.

Best of luck and let us know how you get on!



LOGICAL LAUGHTER: If only all gags were this simple.

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We work with ODEON, Cineworld, Vue and Showcase at over 300 cinemas nationwide.

Once a month, each cinema hosts an autism friendly cinema screening welcoming families, friends and individuals to their sensory friendly films.

Libraries

We've produced a training video and suite of resources to help libraries across the country become autism friendly. These are free for all libraries to use, should they choose to do so.

Ask your library to become autism friendly and show them how important the changes are for you.

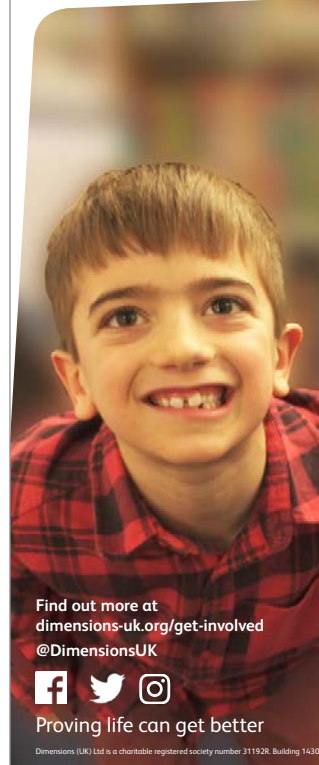
We work in partnership with the Association of Senior Children's and Education Librarians and the Society of Chief Librarians to support autism friendly libraries, in a project funded by the Arts Council of England.

Belong by GAME

We're also working with Belong by GAME to trial autism friendly adjustments at their Arenas.

Belong Arenas are separate areas at some GAME stores where customers can play the latest video games on the latest equipment - including high tech gaming PCs, Playstations and Xboxes.

Belong Arenas are already quiet, welcoming spaces where some people with autism go to meet new people and try new games.



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