



Aukids

Issue 43
Spring 2019

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For Parents and Carers of Children with Autism Spectrum Conditions



Sound advice

Our expert panel on
sensitive hearing



Be our guest!

Disneyland Paris for
kids with autism



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Juggling work
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£89.95!



Letter from the Editors



Hi again!

We may be no spring chickens, but we have chickens this spring on our cover... Gloria, to be precise, posing with her owner Christopher. Now there's a first!

Now, go straight to Page 3 without delay for details on how you can book tickets for our annual fundraiser. Every year after the summer holidays, we post a 'virtual medal' to parents on our Facebook page. This year, we thought we'd go one step further – we thought we'd throw you a party! All funds raised will go towards the production of AuKids.

Our 80s night this September is a chance for parents and friends to let their hair down and enjoy a spot of retro relaxation. As well as a meal and music, there will be plenty of little surprises, so if you're local to Manchester come along, support your favourite magazine and bring your friends!

Many thanks to San Rocco restaurant in Ashton, our autism-friendly superstars, who are sponsoring us by contributing their venue for the night. Now we're not saying you have to dress up, but if you do have any pixie boots, leg-warmers or fingerless gloves lurking in your wardrobe, we won't say no! So, get into the groove and we'll see you there...

Another bumper issue awaits your eager eyes this spring. Our readers Glen and Sally share some priceless information on travelling to Disneyland Paris. Their fantastic experience over three days is truly inspiring to read. Sally did loads of useful research beforehand, which we're delighted to share with you. For those of you who thought a trip like this was beyond your reach, maybe you can think again.

A big thanks to all of you who contributed to our feature on juggling home and work-life. Sharing personal experiences can give us all ideas about how to return to work, if it's what you want to do.

It's always helpful to hear from adults on the spectrum who can articulate their own experiences on behalf of those who can't. We'd like to thank Stasia Gibbs-Lewis for her Inside Angle article this issue. It takes such bravery to put into words how it feels to be overwhelmed, partly because even describing these sorts of episodes can bring them back to a person. Thank you Stasia, your insights have helped to create more understanding.

Enjoy Issue 43!

Tori & Debby



We're a leading North West charity offering specialist autism services to people with ASC and their families.

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WHAT'S IN A NAME?

Orchids are beautiful plants which, much like kids with autism, require very specific conditions to grow. If they get them, they thrive. That's why we called this magazine AuKids. AU is also the chemical symbol for gold.

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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Cover Star



Our front cover star Christopher Eley is 8 and has autism. He currently attends a mainstream primary school in Manchester.

Favourite things Watching You Tube videos of Minecraft and Roblox. Building worlds in Minecraft and in Roblox on the computer. Nintendo Switch. iPad. Reading Captain Underpants books and drawing lots of pictures of Captain Underpants. Building LEGO® models of Minecraft and building different LEGO® mini figures. Going to Waterstones and looking at Captain Underpants books. Looking after the animals especially his chicken named Gloria and his Cavapoo, Georgie. Staying at home with Mummy. Steve and Chris from Gogglebox. Ear defenders/headphones to block out loud noises when we go out. Satsumas and watermelon.

Dislikes Loud noises. People shouting. Busy places. Litterbugs. Grapes. Going places he doesn't know. Not being allowed on the computer. People being mean. Football on the TV.

Mum Julie says: 'When I tell people Christopher has autism they say things like 'it must be so difficult.' The stereotypical view of autism is so far removed from the reality it makes me smile. Christopher is a sweet, gentle, creative, sensitive boy and a shining light in our family. Christopher happens to have autism.'

'Christopher, like his two 'neurotypical' brothers, has his moments. However, we have strategies to help him manage this.

'I am disabled and when I am upset or when I am in pain, Christopher is the first of my children to come to me and either touch my hand or sit with me. When we got our chickens, Christopher's brothers Harry and Daniel were so excited and helped to collect the eggs for a couple of weeks. That soon stopped when the cold weather came. Christopher was the one who continued to collect the eggs, talk to the hens and check on them through the winter.

'When people are told their child has a diagnosis of autism, it can feel like the world is coming to an end. I appreciate everyone's challenges are unique.

'However, our personal experience with Christopher is that his autism is just a part of him being awesome and he has certainly made our little family more colourful and fabulous than it would otherwise have been'.

He Likes:
Captain Underpants and Minecraft

He doesn't like:
Loud noises and busy places

I ♥ 80's

Join us for AuKids 80s Night!

Yes, we know there's no apostrophe in 80s. Try telling our picture library...

Anyway, forget about grammar!

Celebrate the end of the school holidays in the company of other parents who have also spent six weeks making visual timetables and accidentally stepping on Lego®.

'If we took a holiday-ay...took some time to celebra-ate... Just one day out of life. It would be-ee, it would be so nice!'

Let your hair down and hark back to the time when the only thing you worried about was whether Bryan Adams was going to be Number 1 for the 85th week running.

It's going to be a Night to Remember (see what we did there?)

The evening will include a three-course meal (see Eventbrite for details) with veggie option and bad dancing till late.

Fancy dress optional but VERY welcome!

All proceeds to AuKids magazine, a not for profit social enterprise.

Tickets Are £30, available at: www.aukids80snight.eventbrite.co.uk

See you there!

Put it in your diary:
September 7th 2019
7pm-12am, San Rocco restaurant, Stamford Square, Ashton under Lyne (on the A635, nice and easy from the M60).



Who's Behind Our Lens?

David Laslett is a professional photographer and responsible for the gorgeous front covers that you're treated to every quarter. Dave photographs families at their own homes and in his super Stockport-based studio. He also travels around quite a bit and has some special schools on his client books.

So Dave, we asked. What's the secret to taking a great picture of a special needs child who may not be comfortable in front of the camera?

'I think the important thing to remember when speaking to children is not to talk down to them. They're very quick to pick up on that. I like to ask them what they're interested in. Children have a great way of explaining things. I like

to take some time to get to know my subject where possible before rushing into the photography'.

What makes them comfortable?

'Being genuine, being relaxed and calm, and smiling a lot (which I do anyway). If the child is nervous or stressed, it's best to wait till they get used to the camera before photographing them. I show them how the camera works, tell them about what I'm photographing that day and so on. It also helps that I'm a big geek, so at home I get to watch the latest cartoons and animated films with my seven year-old daughter, which keeps me up to date. I know the names of far more Pokémon than I should!'

What's important to you?

'The most important thing to me is to capture my subject in the most natural way possible, whilst ensuring that they are happy and comfortable. I think those images are far nicer than staged pictures'.

Dave is equally happy photographing for individuals and organisations. Do you have a special event you'd like to cover? You can contact Dave at www.manchesterphoto.com or email him at manchestercreativemedia@gmail.com

WIN!

A Rotating Bead Wheel Worth £89.95!

Child development is at the heart of all Learn Well resources. Products are thoughtfully created to give young children and older ones with special needs a broad range of sensory learning experiences. Best known for the old favourite 'Mirror Chimeabout', we are delighted to have launched over 50 new and exciting resources, each made to guarantee a smile!

All of our resources are available through your favourite suppliers.

Rotating Bead Wheel

Research shows that sensory play builds nerve connections in the brain's pathways. The mesmerising rain-like sound and the bright colourful reflections of the sparkling glass beads will stimulate the senses and encourage playful exploration. Rocking the wheel backwards and forwards gives the gentle sound of waves. Spin the wheel and be amazed as the beads swirl and cascade.

Exclusively available from TTS at www.tts-group.co.uk - product code EY10726



Give it a Whirl!

To be in with a chance of winning this rotating bead wheel, just answer this question.

In what year did TTS launch?
A) 1985 B) 1995 or C) 2005?

You can find the answer on their website. Send your answer to us at competitions@aukids.co.uk or via snail mail to AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE. Competition for over 18s only, no cash alternative. By entering this competition you give permission for AuKids to forward the winner's name and address to Learn Well so that your prize can be sent directly to you. Winner to be chosen at random after the closing date of May 31st 2019. **Good luck!**

Reviews & Prizes



BOOK

An Introduction to Autism for Adoptive and Foster Families: How to Understand and Help Your Child

By Katie Hunt and Helen Rodwell
Published by Jessica Kingsley Publishers
£14.99 • ISBN 9781785924057

This book is written by Consultant Clinical Psychologists who specialise in working with children with complex special needs/neurodevelopmental difficulties and with looked after and adopted children. As such, they are extremely qualified and well-placed to deliver a book that most definitely achieves what it sets out to do, which is to provide an invaluable resource for busy foster carers and adoptive parents.

Written in an informal, easy to read style it contains lots of important and useful information to help the reader form a better understanding of autism. Throughout the book, the reader is

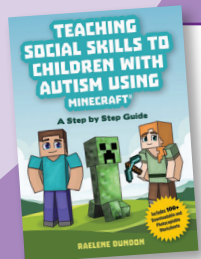
encouraged to think about their individual child - their particular qualities, challenges, strengths, attributes - with the kindly reminder that no two children are the same.

The book is divided into two parts - Part 1 being a comprehensive introduction to autism and Part 2 focusing on the particular issues relating to fostering, the care system and the adoption process. The book explores contact, life story work, attachment and the impact of the experience of loss and trauma.

In addition, the book contains useful principles, strategies and resources for the reader to take forward and use in their practice - including a printable "Getting to Know My Child" appendix.

The book ends with a brief chapter on Looking after Yourself, a golden rule for parenting. I highly recommend this book to anyone aiming to understand and care for a child with autism who also is in foster care or is adopted.

Louise Breen, foster carer.



BOOK

Teaching Social Skills to Children With Autism Using Minecraft®: A Step by Step Guide

By Raelene Dundon
Published by Jessica Kingsley Publishers
£24.99 • ISBN 9781785924613

The historical problem in teaching social skills to autistic children is motivating them to practise something that they find quite alien and uncomfortable. Answer: pair it with something familiar and exciting.

Three years' experience with 30 groups of mainstream autistic children has provided a firm base from which Melbourne psychologist Raelene Dundon has been able to develop this easily accessible social skills course. Groups of 8-10 children of similar ages are recommended - the course is suitable for ages 5-12.

Raelene starts with a brief round-up of the background to this course, the social skills that can be missing in autism and the thinking behind group programmes in general. She follows it up with a whistle-stop tour of Minecraft®, explaining the concept of the programme, in which a gaming session forms the backbone to each group lesson.

In Part 2, she moves to instructions on setting up a session, with lesson structure described in detail. The children are set a particular task to complete on Minecraft® in pairs while working on a specific social skill. They discuss the topic before and after the gaming session and are given a Minecraft® based 'home challenge' to involve parents and give valuable practice and thinking time. Free play is deliberately built in to each session, fostering good relationships between the children, and movement breaks are also suggested to help with regulation and arousal.

This guide is very easy to navigate and yet extremely comprehensive. Sessions are laid out so clearly that you'd need very little experience to make this successful. The course doesn't stint on difficult topics; areas covered include

friendship, understanding point of view, asking for and accepting help, responding to teasing and showing interest in others, to name but a handful.

The book includes downloadable and photocopiable worksheets, all beautifully illustrated - and a rewards section at the back, including Minecraft® 'dollars' and course certificates.

I was unsurprised this was good - Raelene is a mum of three, two of whom have autism, and her previous book *Talking With Your Child About Their Autism Diagnosis* was one of the best autism guides I've read.

What a fantastic contribution she's made with this new guide, which I hope will become as popular as it deserves to be.

Debbly Elley, AuKids Co-editor

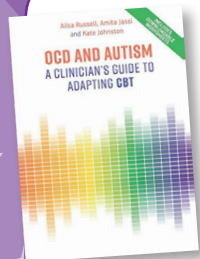
WIN!

A copy of Teaching Social Skills to Children With Autism Using Minecraft® worth £21.99

We have three copies of Raelene's book to give away. Simply answer this question (or ask a young Minecraft® expert to answer it for you!)

Q What is the rarest ore in Minecraft?
a) Diamond b) Gold or c) Emerald.

Send your answer to us at competitions@aukids.co.uk with **Minecraft** in the subject header by the closing date of May 31st 2019. Or use snail mail and write to AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE. Entrants must be 18 or over. Winners will be chosen at random. By entering this competition you agree to AuKids passing on the winners' names and addresses to Jessica Kingsley Publishers so that your prizes can be sent directly to you. Happy mining!



BOOK
OCD and Autism:
A Clinician's Guide
to Adapting CBT

By Alisa Russell, Amita Jassi
and Kate Johnston
Published by Jessica Kingsley
Publishers
£17.99 • ISBN 9781785923791

It's rare that we include a review of a book aimed at clinicians inside the pages of AuKids. This one is an exception, because we feel that parents as well as clinical psychologists need to know it exists.

It isn't unusual for autistic children to develop OCD as a way of coping with anxiety, especially during highly stressful times such as transitioning to a new school.

The most recognised therapeutic method of dealing with OCD is Cognitive Behaviour Therapy (CBT), but there are some stumbling blocks with this method if you happen to have autism as well. Your therapist may be well versed in OCD but not as good as knowing how autism interacts with it. If this is the case, we'd highly recommend you tell them about this book.

OCD And Autism addresses the issue of telling the difference between the repetitive and restrictive behaviours that are part of autism and those relating to OCD, pointing out that the motives are different in each case. This is rather clever, as lines can often be blurred.

It points to the difficulties that autistic people may have in identifying and

labelling their own emotions and gives practical ideas to overcome those difficulties and develop awareness.

On a practical level, it advises helpful overarching strategies throughout therapy, such as creating colourful visuals, making ideas 'concrete' rather than abstract and using special interests as a way of introducing a client to an unfamiliar concept. These ideas are accompanied by downloadable worksheets to make the job even easier.

Throughout, the authors give simple but definite guidance, even suggesting what to say to your client and how to ask questions when they aren't being forthcoming. In addition, there's a few case studies to flavour key points.

As a parent whose child has experienced CBT therapy, I can honestly say that this book has been badly needed and I'm sure will lead to more successful outcomes in the treatment of this miserable disorder that afflicts so many autistic youngsters.

It's a book that could be read in under two hours, and yet for any clinician this will be an invaluable guide.

A word of warning – don't buy this as a parent if you want to learn more about CBT; it assumes prior knowledge and isn't for that purpose. If you're looking for something along those lines, a much better bet is *Breaking Free from OCD - A CBT Guide for Young People and Their Families* by Jo Derisley, Isobel Heyman, Sarah Robinson and Cynthia Turn, also published by Jessica Kingsley.

Debby Elley, Co-editor AuKids

It's like a little sensory room in your pocket!



APP
Cause and Effect
Light Box

By Cognable • £3.99

It's a very long time since we last mentioned Cognable's sensational *Cause and Effect Light Box* and I feel it's worthy of another review, partly because it's been updated and partly because it is easily one of the best apps for autism I've ever come across, so if you weren't an early reader of this magazine I wouldn't want you to miss it.

Originally developed for iPad use (costing £3.99), the Windows and OSX versions of Light Box are free for non-commercial use - including at home or in school. The desktop version includes support for LEAP Motion, mice, multi-touch screens and several other controllers.

Among the Light Box's many assets is its simplicity. Just touch the screen with a finger, move it around and you'll create your own sensory world of colour and sound. With gorgeous graphics, it's

truly mesmerising. Among the effects you can dabble with are bubbles and hot air balloons, leaves that blow in the wind, snowflakes that twirl to the sound of cowbells and stars that glitter to firework sounds.

This app can be enjoyed at any age. The delightful effects are paired with a mix of natural and man-made sound effects, so you can be listening to gentle rainfall one minute and fancy yourself as Jean-Michel Jarre the next.

To swap between effects, you need to press the small 'X' button on the corner of the screen – not too difficult on a large device but you need nimble fingers to use this on your phone.

My advice for parents is to download this onto your phone for waiting times – it is like a little sensory room in your pocket.

To find out more, go to www.lightbox.cognable.com

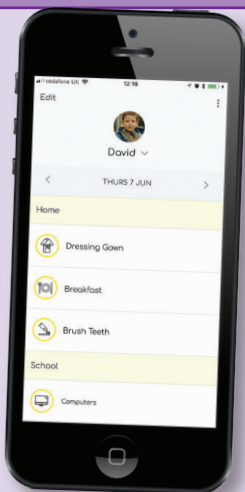
Debby Elley,
Co-editor AuKids

APP
Picturepath

By Nova
FREE (in-app purchases)

What I love about being in the autism community is that you come across so many parents who have addressed a gap in the market using personal experiences. One such parent is Richard Nurse, whose young son Freddie inspired the Picturepath app at www.mypicturepath.com

Like most of us, Richard was a bit tired of creating visual timelines using paper and laminators. Using Picturepath you can create your own visual timeline on your phone or other device (it works across all Apple and Google Play devices). What's even cooler is that you can change the timeline at a moment's notice. You can choose from a range of symbols (they aren't PECS symbols) or upload your



own images and you can physically push the icons around the timeline to get them in the right place.

The web version of this app has been developed for use by schools, so that changes of timetable can be accommodated easily. There are a number of helpful mini tutorials on YouTube in which Richard demonstrates how to create and edit a timeline.

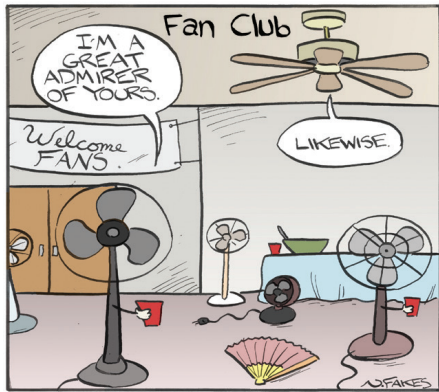
A word of warning, if you try to create more than a single routine on the free version, it won't let you. The basic

version of Picturepath is free but for £1.99 a month you can add multiple routines and share them. This is the best way of using the app in my view.

This is an initiative we should invest our time in, so if you use it do offer feedback to the app designers through the website so that they can continue to add to it in subsequent versions.

Debby Elley, Co-editor AuKids





“ I’m a teacher doing some work with a lad who is the most noise sensitive I have ever come across. He likes white the noise of fans but we aren’t sure why and we don’t know quite how to help him. Any ideas? ”



Phoebe Caldwell

Phoebe is an expert practitioner in Intensive Interaction and trains professionals, therapists, managers and carers in the approach.

Noises can be excruciatingly painful but quite often it is certain frequencies causing the problems and children (and adults) will try and block out these frequencies by ‘drowning’ them out with other sounds, such as tumble-dryers or occasionally white noise.

As with all autistic people, the exact way that sensory sensitivities show up varies from child to child. In many cases, we have found that BOSE noise acoustic reduction headphones models 15 or 25 are very helpful. Designed for helicopter pilots, these cut down background noise and unlike ear defenders, do not reduce all incoming

sounds. They can still hear sounds and their teachers – and we have had dramatic improvements in both attention and behaviour. In particular, one cannot judge the level of a child’s cognitive ability while they are struggling with the pain caused by auditory hypersensitivity, as well as the anticipatory anxiety that a noise may happen (since anxiety interferes with sensory processing). Sometimes their performance shoots up.

BOSE headphones are not cheap and it is worth shopping around as prices vary. Also one cannot guarantee they will answer the problem for a particular child. But all schools should have a pair so that they can scan children with autism since the problem is fairly widespread. Also, any extensions or new-builds should incorporate acoustic panelling.

May I suggest you watch the free training film, ‘Responsive Communication’? It lasts for three hours but is subdivided into 26 shorter episodes and covers both sensory issues and using body language to establish engagement. You can find it at www.thecaldwellautismfoundation.org.uk/index.php/responsive-communication-the-films

Phoebe’s new book on **Responsive Communication and Sensory Issues** is being published later this year by Pavilion.



Becky Lyddon

As founder of Sensory Spectacle, trainer and speaker Becky Lyddon creates awareness of Sensory Processing Difficulties. She works alongside people with SPD to create immersive learning environments. You can find out more at www.sensoryspectacle.co.uk

Many of the adults with Sensory Processing Difficulties (SPD) who I work with to create my immersive environments explain difficulties with organising and filtering out sounds. In the classroom this can be particularly difficult especially with all of the added ‘invisible’ sounds that many of us may not even notice.

We process sound through vibrations. Therefore anything that creates a vibration, our brain interprets as sound. We all learn to tune into specific frequencies as the auditory pathway in our brain develops. Technology is probably the most disrupting thing in classrooms now as it will be making a high frequency sound which some people will be tuning into, just like lights buzzing, radiators humming and our own bodies!

It might be a good idea to observe him and where he sits in the classroom. He may have found a spot in the classroom which supports his sensitivities. If you are

working with him in another space you could try different areas to see which he finds less distracting.

A classic characteristic for people who are hyper-sensitive to any sensory input is a need to ‘feel in control’. This is because they are less likely to be able to manage and regulate their responses to sensations that are spontaneous. Fight and flight is a primitive response that we all have and will trigger in times we receive an extreme stimulus. For some of us that might be a big loud ‘BANG’, for others it might be a specific intensity of light.

For people who are hyper-sensitive, their brain is alerting them to many sensory messages and being told they are all important. This is why we recognise physical responses a lot more frequently for people who are hyper-sensitive.

Some people with SPD can be in extreme pain from their hyper-sensitivities so responses to small inputs may seem exaggerated but it may be that they have an intense headache (for example) because of a specific sound or smell.

When we have plenty of opportunities to process a sensation, our brains recognize the input easier. White noise is a collection of frequencies which we are most familiar with and sound similar to when we were in the womb. It can therefore be really comforting.

Before supporting anyone with SPD it is important to identify their over-riding sensory needs, these are the sensations which impact their daily life the most.

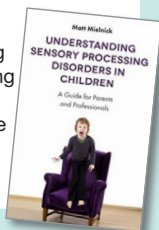
No-one is the same and sensory processing is a personalized system. So we need to be flexible, observe the child and how they support themselves and then add in extra strategies to promote self-regulation.





Matt Mielnick

Matt is a Paediatric Occupational Therapist with 20 years of experience working with young children, providing evaluation and treatment services in New York and Massachusetts. He is the author of *Understanding Sensory Processing Disorders in Children - A Guide for Parents and Professionals*.



A child's strong responses to sound, light or touch may be partly in response to a significant medical history that is characterized by ongoing discomfort (such as protracted bouts of reflux or chronic ear infections). These long-standing discomforts can eventually permeate a person's entire disposition and inclines the child to approach all but the most secure settings with apprehension.

Similarly, such defensiveness may be the result of some early trauma that can't be put to rest.

Alternatively, some children are simply born with a highly responsive nervous system that predisposes them to immediately guard against perceived threats.

Here is what they all share in common:- Our normal day to day engagements are governed by the frontal area of our brain which we depend on for judgments, reasoning and limit-setting. When faced with a perceived threat, blood flow is diverted to that part of our brain that engages our protective fight or flight mechanisms.

If this stress becomes chronic, our reasonable brain goes into 'sleep mode' and brain management is handed over to the emergency systems, which really only do a good job during emergencies.

This leaves a brain that eventually responds too quickly and too strongly to specific stimuli.

A child with strong auditory sensitivity is really struggling with their strong anxious responses to these stimuli. It is perhaps more

helpful to look for ways to reduce their anxieties as it is to look for some magic bullet to reduce their auditory defensiveness.

My first suggestion is to have your child tested for any significant vitamin or mineral deficiencies. Deficiencies in Vitamin D, B vitamins, iron and especially magnesium can leave a child ill-equipped to deal with anxieties.

It is helpful to keep a log during the school day of those events or settings that typically result in protest or discomfort complaints. For example, always prepare the child for alarms, bells, and loud speaker announcements.

Visits to the cafeteria, gym class, assemblies, and recess, can all put the auditory defensive child on high alert. A pair of noise limiting (not noise cancelling) earplugs can be given to the child to wear for these times, and then collected upon returning to the classroom (don't allow the child to wear these throughout the day as tolerances will be even lower when they're not being worn).

It can also help to listen to a 'pink noise' recording at a desk with ear buds for quiet work times. This can be especially soothing. Pink noise is white noise, but with reduced higher frequencies. Examples are steady rainfall or wind, often considered to be more soothing than white noise, which some people find unpleasant. There are free pink noise apps available on Amazon and other app sites and pink noise CDs are also available for purchase.

In early learning classrooms, the teacher might identify a safe spot such as a small one-person tent with pillows that the child can retreat to when troubled. Regular exercise breaks – like tug o' wars, trampolines and obstacle courses can also offer great stress relief.

I know some therapists that strongly endorse Listening Programs* for children with auditory defensiveness. The one that I've heard the most positive comments about is the Integrated Listening Program (they have a Home program available).



*Editor's note: We asked the NAS research team about this intervention - unfortunately there is as yet insufficient evidence to prove its efficacy, but for research on auditory integration therapy please see this link: www.researchautism.net/interventions/4/auditory-integration-training-and-autism

Please note that Matt was referring to the Listening Program, not this kind of therapy in general, in which success rates vary.



Emily Kellett

Emily is an Occupational Therapist with the Seashell Trust charity www.seashelltrust.org.uk

Noise sensitivity occurs when the central nervous system receives a stimulus from the environment (in this case, noise) and interprets it as being a potential threat. This stimulates the body's fright, fight and flight responses. This natural response typically protects us by triggering our bodies to react quickly and keep us safe from danger, but in this situation, the information has been misinterpreted.

Our brain's ability to learn and grow and to adjust our responses to changes in the environment is called neuroplasticity. This is an amazing tool in supporting recovery and development, but not so great when everyday responses to sound become perceived as negative. When the fright, fight and flight response is triggered, we build new neurological pathways within our bodies. If this happens frequently, the pathways grow stronger and more powerful and can almost 'override' the part of our brains which tells us that the sound we are hearing is 'OK'.

It can reach a stage where a person can no longer process the noise as being anything other than dangerous and something needing a rapid response; either fighting it (becoming physically or verbally aggressive) or withdrawing and avoiding it completely.

At this point it is very important that a response is understood and carefully managed. It is not a case of a child being 'naughty', more that they simply cannot control their body's responses to certain stimuli and experience exceptional levels of stress and anxiety which may hugely impact their everyday life.

Generally, we are able to tune out background noise within our environment and attend to what is needed (we don't 'hear' humming of the lights, someone chewing or stirring their drink), however, if sound is distressing for someone and they've become hyper-alert to it, it becomes impossible to block.

White noise can help to mask out the environmental noises which occur on a daily basis. The sound is predictable and reassuring and does not block out other sounds like ear defenders would, enabling a youngster to remain aware and in control of their environment. White noise playlists can be downloaded to portable devices which can be transferred to community settings so that pupils can function better. I would always (if possible) advise against using ear defenders as these can make noise sensitivity worse in the longer term.

Activities rich in tactile and *proprioceptive stimulation are known to reduce sensory sensitivities, including sound. Tactile and proprioceptive activities which may help include deep pressure massage, exploring vibrating objects and weighted equipment. Activities that encourage resistance against the skin and joints and muscles such as swimming, cycling and running are also really beneficial.

Those activities help because they begin to calm the central nervous system and dampen the negative responses to stimulation, leaving a young person feeling more comfortable with managing situations which are stressful for them.

*Proprioception is our physical sense of where our limbs and joints are positioned in relation to the space around them.





Our Magical Trip to

Disneyland® PARIS

Sally and Glen Toman always take their three children Harry, 8, Izzy, 7, and Freddie, 6, on holiday during the summer for Freddie's birthday. Harry and Freddie both have autism and Harry has ADHD as well. Both Harry and Freddie value their routine, so a holiday can be overwhelming at times. It seemed ambitious to aim for a trip to Disneyland® Paris, but the family told us they had an amazing time, thanks to the park's accessibility.

Sally reflects on how difficult family holidays have been in the past: "Harry does look forward to holidays but sometimes it gets too much for him. It's all built up and then all of a sudden we're here and he wants to do this, this and this RIGHT NOW! He can get angry and frustrated and has a tendency to run off. Freddie needs constant supervision and he can't queue, he doesn't understand that he has to wait."

After deciding on a trip to Disneyland® Paris a year in advance, Sally and Glen embarked on plenty of research. Sally made use of the website's e-mail contact form for guests with disabilities and found it very helpful.

The couple also found Disneyland® Paris's Facebook page for guests with special needs. "There's people there who've been and done it and who go constantly," says Sally. "They are full of information."

Their research revealed that carers go for free, and only having to pay for the children represented a saving of more than

£300. The couple also found out about Disneyland® Paris's special Priority Pass – known amongst visitors as the 'green pass' because of its colour. Priority Passes allow visitors with autism to go through a separate entrance and get straight on each ride.

Like many children with autism, Harry and Freddie had a small number of favourite rides that they wanted to go on repeatedly and in one case the pass reduced the wait from 50 minutes to nothing.

Once at Disneyland®, a machine prints out tickets and you're then required to visit City Hall inside the park to collect Priority passes and lanyards.

Disneyland® has just updated its criteria for qualifying for a Priority Pass, so the family's advice is to take plenty of proof of disability. The Tomans took a Blue Badge disabled parking permit as proof for Freddie and Harry's proof of Disability Living Allowance (DLA). The park needs the DLA letter to be dated within 3 months of the visit, so Sally called the DLA and asked them for proof of entitlement within three months of their travel date, which they provided.

The family also took a letter from Harry's psychiatrist confirming his diagnosis and that he had issues queueing. Sally found out that their GP charged £30 for a similar letter, so advises you try another of your children's specialists.

City Hall provided the family with a Disneyland® Park accessibility map, telling them how many visitors with autism were allowed on each ride. Only one ride was out of bounds for visitors with autism, because the evacuation process for it was complex.

Many of the rides are wheelchair friendly (the disability guide states which), and Freddie's buggy was allowed on The Thunder Mesa Riverboat Landing ride.

The family found staff clued up and friendly.

"We wore the passes on lanyards and at one point we were trying to get from Frontierland over to where Star Wars Hyperspace Mountain was, but the parade was just starting. We went up to someone, they looked at the badge and whisked us straight there. Any time you asked a question they would see the badge and tell you exactly

Magic Carpet?

The Tomans took their own car and used the Eurotunnel. Sorry.

The Bare Necessities

A two-park ticket including entrance to both Disneyland® Studios and Disneyland® Park (in 2018) for three days was £132 each per child via the Picniq site (www.tickets.picniq.co.uk). Sally recommends you compare ticket sites. If you buy tickets while you are there, Disneyland® gives you a 10% discount on your Disabled Person's ticket price.

Be Our Guest!

The family stayed in a campsite called Paris Est, just off the motorway and 32km (19 miles) from the park. It's about 25 minutes from Disneyland® with no tolls on the way. They hired the cheapest caravan, which they described as basic, and used it purely as a base to sleep, shower and have breakfast.

Paris Est is at 110 Boulevard des Alliés, 94500 Champigny-sur-Marne, France – you can book through www.booking.com





'On the Buzz Lightyear ride you got lots of chance to score points by shooting lasers at things!'

where *you* needed to go, not where everyone else was going.

"Because we kept going on a lot of the same rides they started to recognise us and they learnt the kids' names."

Meals were the only limiting factor. With picky eaters, the family had decided to eat at their caravan in the evening, but found it only had a microwave. "We did end up living

Tips from The Tomans

- ♥ Prepare your child in advance of the visit by showing them pictures of the Eurotunnel train and looking up rides on YouTube.
- ♥ Parking costs 25 Euros a day. You still have to pay if you have a Blue Badge, but show it at the parking booth and you're given a code that allows you to park at a Disneyland® hotel. These are much closer to the entrance.
- ♥ If you stay at a Disneyland® hotel, parking is free.
- ♥ City Hall gets chocca bloc – get there first thing in the morning to collect Priority passes.
- ♥ Take drinks and snacks because they're expensive on site.
- ♥ Wear decent shoes! The family covered about 10 miles a day (with piggy backs and shoulder rides!)
- ♥ Illuminations start at 11pm and the Tomans reported they were 'stunning'. There is priority seating at the illuminations for disabled visitors and the family were advised to arrive an hour early.
- ♥ Bring a picnic blanket and something to eat whilst waiting for the illuminations to start and pack ear defenders for the fireworks if needed.

at McDonald's in Disney," says Sally. The family thought that other dining outlets were quite expensive and at the time they went, not brilliant for restricted diets. They'd recommend cooler backpacks for next time – cool boxes aren't allowed but these are.

The family also found the Disneyland® Studios next door disability-friendly. The children loved the stunt car show there. Once again, the family were able to use their Priority Passes to avoid queueing. There was no need to arrive in advance; disabled visitors and one carer can sit in the front row, with family members sitting directly behind them. Disneyland staff were vigilant about this.

The three days proved to be remarkably relaxing, even for these parents.

Glen admits: "I was dreading it because we'd had bad experiences over here...I thought at the most we'd be doing two or three hours daily, but we were there for eight or nine hours a day. I couldn't believe it. They got so much out of it and the passes really made the holiday. It was so busy but because of the priority treatment it felt like it was shut - they made you feel like you were the only ones there".

Sally agrees. "I found it a massive stress-buster. I screamed on all the rides! All those years of everything building up – I just let it all out!"

Perhaps the most valuable element of the holiday was that Disneyland® provided a place where the entire family could stay together. Glen says: "We do things separately all the time to keep everyone happy, as our kids all have such different needs. So for the five of us to be together all at the same time was so good – it was just really nice to see them all enjoying themselves".

A Whole New World

- ♥ Website: www.disneylandparis.com
- ♥ Find the Facebook closed group by searching Disneyland® Paris - Special Needs or Disabilities
- ♥ Manual wheelchairs and strollers are available to rent at Disneyland®.



BUGGY ON BOARD: Some rides allowed Freddie to use his buggy.

What the Kids Said...

"Hyperspace mountain was soooo amazing because you got to ride in a magical rocket that was sooo fast and a bit scary!"

"Big Thunder Mountain was really fun because it was fast and it was like back in time when everything was made of wood".

"The green passes we had were amazing because we never had to wait for anything and could just go straight on every ride with no queues. And we got to sit right at the front when it was the parade and the fireworks".

"Mickey Mouse even spoke to Freddie on the phone to wish him Happy Birthday and the lady said it with sign language to him, too!"



The Girl on the Train

Stasia Gibbs-Lewis is a 37 year-old autistic woman and mother of an autistic son. Since her diagnosis at the age of 33 she has become a public speaker on autism and alongside two clinician colleagues has set up the autism consultancy ASPIElutely Fabulous at www.aspielutely-fabulous.co.uk She speaks on behalf of the National Autistic Society and regularly gives guest lectures at The University of Manchester and Liverpool University.



I'm going to begin with an absolute truth I've learnt, having lived many years believing I was a defective 'neurotypical' before my late diagnosis and discovering I've actually been an impressively resilient Aspie!

This world and autistic people are not entirely compatible. This is where most of our difficulties come from, not necessarily from autism itself. But even in a topsy-turvy world, we're capable of utterly delightful lives if we learn how.

I've always struggled with my experience of life...having sensory overloads, social overloads, meltdowns, shutdowns and autistic burn outs without knowing that's what they were, much less how to negotiate them to reduce impact.

These unregulated experiences are harmful; before diagnosis I believed I was broken and suffered fragile mental health. The issue? I didn't know the cause so couldn't protect myself, avoiding or preparing for triggers.

Multiple crises later I reached breaking point - I needed to understand what was going wrong. Skip forwards considerable research and self-exploration to assessment day. There I was, my life in a clinical report. I am autistic!

This didn't immediately address everything, far from it, but proved a solid platform to begin learning about myself. I'd reached 33 with no idea who I was, why I was, or how I was, much less that I had a perfectly impressive brain. It's just **different** from how I'd believed it to be, so I assumed it 'broken' as I tried, and was expected to, just make it work in a way it simply couldn't.

I *still* haven't got it *all* figured out yet. As you will appreciate from your own experiences, autism is a constant learning curve! But in the years since, I started to re-engineer my life, how I function best and happiest in it. Learning healthy coping mechanisms, how to self-regulate and the importance of self-care. These days, I have a mostly thoroughly positive life experience!

Most 'autistic struggles' can't be outwardly seen. They are invisible internal battles fought between our nature versus our incompatible world. Our reactions or failure to cope is what you witness.

One example: sensory processing disorder

is a common feature of autism. It means we struggle to process some or all of our senses - sight, sound, smell, touch, taste, vestibular (body movement awareness) and proprioceptive (body position awareness).

This is because unlike the non-autistic brain which is able to predict, anticipate, define and filter only relevant information, the autistic brain operates a hyper awareness of absolutely everything!

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"Most 'autistic struggles' can't be outwardly seen. They are invisible internal battles fought between our nature versus our incompatible world. Our reactions or failure to cope is what you witness."

.....

We're less able to disregard the unimportant 'white noise' or irrelevant backdrops. Our senses are flooded, everything jostling for our immediate attention with no distinction between differing levels of importance. It leads to sensory overloads, meltdowns, shutdowns and autistic burn outs.

I particularly struggle processing vestibular and proprioceptive sensory information. My sense of where my body is in relation to the ground is under-sensitive, unless solidly established on a firm footing. Escalators are my nemesis! My inability to feel safely planted to the ground induces very physical anxiety symptoms.

The steps moving away from me just don't seem to relate to my reality. That visually distorts and elongates my view of them, exaggerating the downward stretch. The handrails move at different speeds to the steps so offer no reassurance of steadying myself.

My vision warps, tunnels and my peripheral vision blackens. The overwhelming noises

all around stay as loud, but muffled - like suddenly miles away, but without losing volume. My heart pounds too hard as intense anxiety washes over and drowns me. I can't breathe, I go light-headed and it's all I can do to cling to the walls to keep from fainting and to claw myself away somewhere 'safer'.

With any autistic crisis it becomes everything. Only that and absolutely nothing else exists for us in that moment. It is all consuming, sometimes with such intensity we feel we could **physically** black out from it. Powerful enough, it feels, to accelerate the spin of the earth!

I self-regulate myself away from the 'cliff edge' of this crisis until I can get somewhere appropriate to fall to pieces *safely*. I seek to replace and override the intolerable sensory information with other sensations. I **sensory seek**. I stum my fingertips across varying textured vertical surfaces as I walk the edges of the railway station, getting those drumming sensations that seem universally irresistible to children walking alongside fence railings.

I hyper focus. Opening my phone, I start writing about it on an autistic adults' page on social media. Writing so intently, reading and responding to people's replies helps me blinker out my surroundings as I crudely navigate myself to my train home. I sink into a seat, shrink myself...becoming as hidden as possible. Hyper-focusing on my typing is keeping me from losing emotional regulatory control.

Home and 'safe' now, I can stop suppressing this need to shut down!

I isolate myself, I am undisturbed, I let go, I am still.....I recover.

I recover.

Self-regulating when I was able, allowing myself to let go when it was safe and allowing myself self-care to recover.

With the right skills **we recover**.

We're inherently resilient people overcoming obstacles everyday - **as standard!** - coping and thriving rather remarkably in this ill-fitting world.

Doorstep Drama!

You had planned this afternoon perfectly, but you can't get out of the front door. One small family member has surprising strength of will when it comes to resistance. Why does it have to be this hard? Here's some tips to prevent it from happening.



Understand Why

Knowing why a youngster with autism can't just saunter out the door with a moment's notice is half the way to solving this battle.

Autistic people don't have flexible thinking. Flexibility of thought comes from being able to tie many different experiences together, generalise and make sense of them. It takes long-range brain connections. Some of those long-range connections don't work as well in an autistic brain (the good news is that short-range ones can work extra well). This means that anything new can feel truly threatening. They're not being awkward or silly, they're frightened of change.

This is particularly the case with very young children, who haven't the solid experience to know that things generally turn out okay.

When, Who, How, What?

As well as telling them when you are going, it's important to let them know who they are going with. This will give them a vital point of stability. How are you travelling there? If it's a train or other public transport, make sure they have an image of this, too. The question that often remains unanswered is 'how long?' Again, it may seem obvious to you that you're bound to be back for tea time, but if you're a routine lover, knowing when you'll next eat is vital. Tell them how long the journey will be, how long you will be staying for and when you'll next be eating (even if it's just a snack).

For non-verbal children, use an image of your transport, the place, the people you may meet there (if friends or family) and a symbol for mealtimes.

Heads Up!

Warning too early can raise anxieties and build up resistance. Too little warning won't be enough. It's a tricky one and every child responds differently depending on the level of change they're about to experience. You'll find with practice that you can judge this best yourself. If you're heading for an afternoon out somewhere new, it's reasonable to give warning a day beforehand.

Start Small

It's important not to demand too much at once. You'll risk losing your child's trust and experience resistance the next time you go out.

So, go somewhere for a short time and **QUIT WHILE YOU'RE AHEAD!**

What autistic people don't know instinctively, they learn from experience, so building up a series of small positive experiences will reap rewards in the long-term.

Make a Difference

We've all relied on one place that is an easy trip, like a special needs toddler group. That's great, but make sure that you build some new experiences into the routine as well as the familiar. The earlier that your child has positive experiences of new places, the more flexible they'll be outside their comfort zone as they grow. But...and it's a big BUT...they have to feel safe and in control when they leave the house. That means preparing them.

Look Back

After successful trips make a little album to review together. You can use it just before your next trip!

Reassurance

Some resistance will be due to a child fearing sensory discomfort. If this is the case, offer reassurance and build up trust by minimising environments that will cause sensory discomfort (their first new trips may be better outside) and packing ear defenders or other sensory calming toys if you're indoors. If an environment is overwhelming and you start to see signs that it is, don't leave it too late – build trust by leaving early. Kids have to know they can rely on you when they're in a new environment and things are out of their own control.

Unseen Upset

Keep in mind invisible factors like fatigue or negative associations. If something negative happened in one setting, your child may link that place to feeling upset.

Exit Strategy

What are they going to do if they feel overwhelmed or don't like it? When a child says 'No' this may well be the source of their anxiety.

It's fine to say 'If you're not enjoying yourself, we will leave earlier' but we'd recommend keeping to solid timings, like: 'We will try it for half an hour and if you enjoy it we can stay longer'. This anchors them and gives them a point of reference at what's considered a reasonable amount of time to stay. Expect to be asked 'How many minutes to go?' during the excursion. This is anxiety working its magic. For autistic children, having sight of the end point makes the new experience itself easier. If you have a Time Timer app to physically show the time left, so much the better. Give ten and five minute countdowns before you leave.

Show and Tell

Autistic people are visual thinkers, so the phrase 'a picture speaks a thousand words' really was made for them. Find images of the new place on line. You Tube videos are also handy preparation. Print out a photo, or have it on your phone. Don't just show it once; show it often, repeating calmly what you're going to be doing (not excitedly – this can raise anxieties as your mood is unpredictable). Don't use a lot of language with the images, just short and meaningful sentences. That way they won't have to process two lots of information at once.

Keep calm

If you meet with resistance going out, getting angry can build anxiety to the point of meltdown. Put something familiar and attractive in the car (a new sensory toy perhaps) and build in time for delays if you can.

Actions Speak Louder Than Words

Debby Elley is the co-editor of AuKids magazine. Author of the book *15 Things They Forgot To Tell You About Autism*, she is also mum to twin teenage sons with autism. She launched AuKids with speech and language therapist **Tori Houghton** ten years ago. Tori runs Time Specialist Support, a support agency in Manchester for youngsters with autism.



Debby Elley



Tori Houghton

It's only two letters, but what if you haven't the ability to say **'no'**?

For autistic children, actions can definitely speak louder than words – in fact, if you don't have many words to start with, they're the only avenue.

Youngsters with limited verbal language can be extremely creative at using the signals they do have to convey they're not entirely happy with something.

Over the years, Debby's non-verbal teenage son Alec has become a master of this.

Alec knows that if he uses the Makaton sign 'toilet', an adult immediately removes him from the room and takes him somewhere quiet where no demands will be placed on him. It's quite complex to sign 'I don't like being on stage,' so he uses 'toilet' as a shortcut for 'I'm a celebrity, get me outta here!'

Our reader Ali Palmer has the same experience with her son Harry. "Harry asks for the toilet using his talker when he's bored or it's noisy in assembly. Plus, when he's had enough, he says 'Goodbye!' to all professionals".

Dr Heather MacKenzie, a speech and language pathologist, says: "One young fellow I knew would go and get visitors' shoes and coats and hand them to the people he wanted to leave. Sometimes it ended up being a little more like he was

throwing these things at them - depending on the urgency".

Neelam, a support worker for co-editor Tori's agency Time Specialist Support, says that one of the kids she works with has realized that 'See you next time' means the person usually leaves. "If he doesn't want to wear his jumper or coat, he'll say 'See you next time!'"

"Fred's good at this," agrees Glen, whose family reviewed Disneyland Paris for us this issue. "He says 'bum change!' to get out of his car seat and attempt to escape".

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"They need to learn to recognise the early 'No' signals that their bodies are giving them, how to communicate this to others and how to self-calm."

.....

All these children have demonstrated that for autism, signs and words don't necessarily have one meaning. Instead they have learnt what these can *achieve* for them in a variety of different contexts.

That limited language works hard for them!

Sometimes autistic kids use repetition of language heard on DVDs or in games to express how they're feeling instead of using the usual terms. Alec's twin brother Bobby used to shout 'I'm LOST, Andy is GONE!' from Toy Story whenever he felt anxious and confused.

This is a kind of 'cut and paste' form of expression and it's really effective, that is if you pay attention to the message conveyed and the body language that accompanies it rather than the words themselves. If you started to think 'But you're *not* lost and we don't know any Andys' you'd be scratching your head.

Because of this, it's important to observe closely what usually captures your child's interest. Most parents don't have any trouble recalling the Thomas the Tank Engine episode they've heard 1,001 times but we need to be mindful that teachers and other carers may not have been present when the youngster originally saw that episode and learnt its emotional context.

So unless there's a translator to explain that, for instance, 'I'm a really useful engine!' can mean 'I'm proud!', your child's teachers may feel flummoxed.

There's a couple of things we can learn from our range of non-verbal anecdotes, says Tori. The first is to make sure non-verbal children are given simple choices daily to get them used to communicating

Although Maria couldn't actually say 'Get Lost!' it didn't take much imagination to figure out she meant it.



their preferences.

“Before you make a choice for them, ask yourself whether that’s something they could decide for themselves,” she says. “Given two choices, could they select the top to wear, or the drink they’d like?”

Another important lesson is to give your child clearer ways of saying ‘No’ or expressing dissatisfaction.

Tori says: “If they can’t get that message across in one way, they’ll try another – and although it’s often funny it’s not always helpful.

“Make sure that any symbols or signs they use include not just what they want, but also what they don’t want. So, next door to the symbol ‘I want’, have ‘I don’t want’. Next door to ‘Come here,’ have ‘Go away!’ If they can use sign language, ‘modelling’ (or showing) them the ‘No’ sign when you say ‘No’ is equally important as showing them the ‘Yes’ sign. Also ‘model’ the word ‘No’ when you understand that they mean ‘No’ but they’ve used another way of expressing it, like throwing something or turning away”.

The ‘get me out of here!’ toilet sign is an escape route for a child with limited language, but let’s not forget that verbal children also need a quick exit. They can quickly become so overwhelmed that their language escapes them and this also presents problems. Language isn’t easy to them and so in times of trouble, it’s the first to abandon them. This is inconvenient and sometimes meltdowns are the only way they can rid themselves of their built-up tension or pain.

In this case, they need to learn to recognise the early ‘No’ signals that their bodies are giving them, how to communicate this to others and how to self-calm. This is no easy task for an autistic child, but Dr Heather Mackenzie’s SPARK programme, explained in her book (see right) is full of great practical advice.

Escape routes for verbal kids can take the form of easy to hand visuals. We’re big fans of the simple traffic light visual for younger kids, who can point to amber when things start to go wrong. Sometimes even having ear defenders around for comfort can be enough to show a child their escape route.



Greg Loynes

Outreach worker Greg Loynes, who is based at the Together Trust’s specialist setting Inscape House School, says that he gives cards to pupils for when they are feeling overwhelmed, to show teachers that they need to leave a lesson instantly.

“Some pupils are happy to accept a ‘Go Out’ card and use it appropriately...Clearly there needs to be a plan behind this, though,” he explains. “What is ‘Go Out’?”

Where do I go, what do I do when I get there, how long does it last and how do I come back?

“If this is being used as a calming a strategy then the ‘Go Out’ place needs to be somewhere that works as a calming place for the pupil....this is rarely the ‘quiet room’! Often our students want a walk round outside....sometimes even off campus to get away from it all for a bit”.

Disruption in the classroom is sometimes caused by autistic pupils feeling that they have to pay attention, but not knowing how long a task is to continue before they have a break. It’s really important to clearly signal how long a task is, what exactly is expected, when their ‘pit stops’ will be and what happens next. This is equally true for both verbal and non verbal children.

We’ve also come across some nice classroom tools that can be used by autistic children to signal how they’re feeling when verbal communication becomes too difficult.

Finally, it’s important to recognize that some non-verbal children use resistance and disruption as a means of expressing identity. As Jonas Torrance points out in his brilliant book *Therapeutic Adventures for Children with Autism*, the system of ‘doing for’ and ‘doing to’ non-verbal children with autism takes their power away. Talking about a non-verbal young lady in his care many years ago, Jonas says:

‘She was not in any way seen as anything more than somebody for whom and to whom things are done...It was only when she was disruptive that some sense of self emerged and could be seen. This is how important challenging behaviour is. Her ‘naughtiness’ was pretty much all she had left in terms of an identity. When we meet someone like this, it’s vital that we don’t smother and negate their behaviour. Their behaviour is their voice and we have to listen’.

Here’s where providing choices is such a key part of nurturing self-expression and self-esteem. At first, a child may not be used to choosing and seem indifferent to the choices presented. But soon, frustration reduces as a result.

So before interpreting actions as playing up, reflect on just a few questions:

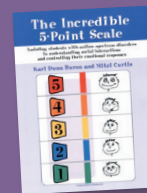
- **What are they really trying to tell me?**
- **Have they been given a better alternative to tell me this?**
- **Have I demonstrated to them that I have understood that message and recognised their feelings?**
- **Do they have a healthy means of escaping this situation if it becomes too much?**
- **Do I give them any other outlet for self-expression?**

Our kids can only use the best tools they have to tell us how they feel.

Further Reading



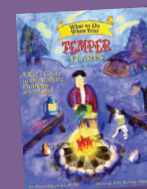
Therapeutic Adventures for Children with Autism
by Jonas Torrance
Jessica Kingsley Publishers



The Incredible Five Point Scale
by Kari Dunn Baron
AACP



The Autistic Child's Guide: Presenting Spark* (Self-Regulation Program of Awareness & Resilience in Kids)
by Dr Heather MacKenzie
Wired Fox Publications



What to Do When Your Temper Flares: A Kid's Guide to Overcoming Problems with Anger
by Dawn Huebner
Magination Press



15 Things They Forgot to Tell You About Autism
by Debby Elley
Jessica Kingsley Publishers

Videos



The ‘Responsive Communication’ series from interaction expert Phoebe Caldwell at www.thecaldwellautismfoundation.org.uk/index.php/responsive-communication-the-films/

Products



Chewigem sell ‘Emotichew’ chewable bangles with ‘talk to me’ on one side and ‘leave me be’ on the other.

You can also buy a Chewimoji to give clear signals www.chewigem.co.uk/product/chewimoji/

The

JUGGLING ACT

Amialya Durairaj is a health writing consultant at Little Octopus and the co-creator of Mindful Return's Balancing Career with a Special Needs Baby programme, the first e-course and community for mums of infants and toddlers with extra needs. She lives in San Diego, USA with her husband and twin daughters, both of whom have special health needs.



For many parents, raising a child with autism can be more than a full-time job. Trying to juggle multiple therapy appointments and school meetings while maintaining a structured routine is a recipe for overwhelm. Sometimes it can feel impossible for parents to balance their careers with all of their caregiving responsibilities. That's why many parents of children with autism will choose to take a step back from work to be full-time carers.

In spite of the many difficulties, some parents of children with autism have managed to balance their work and home lives. I spoke to some working parents of children on the spectrum to find out how they did it. Here are some tips from what I've learned from these families:

I start work at 10.30am which means the school rush in the morning is only about the kids. I'm not trying to get me sorted too so it's less stressful.
- AuKids reader Jo Sandy

a three or six-month trial period before they commit.

Even talking to your boss to build in a little wiggle room for sick days or unexpected calls from the school will be a huge weight off. Planning before the crisis occurs will help you stand out as the kind of employee that your employer can rely on - a win-win!

Setting up your family structure so that one partner is the flexible one can also work well for some parents. AuKids reader Rachel Wood says: "We have three children, two on the spectrum. Hubby works full-time so it was important for us and the children that one parent is always around, it works well for the holidays, appointments and when they are sick. I work from home as a self-employed ghost writer. I love it, it gets my brain working and the kids are settled knowing I am here and we have our routine with everything at fixed times each day."

Don't have a job with flexibility? Consider crafting your own. Heather Anderson found herself in this position when her life as editor was incompatible with her life as a single mum. "When news happens, news happens," she said. "And I would have to drop everything. So you need to do something flexible enough. That is why I'm a big supporter of self-employment when you have a kid with special needs." She currently owns two businesses, including Autism Oasis, an online resource for parents.

Tip 2: Build resilient support systems

Sadly, there is only one of you. Until technology advances to the point where you can clone yourself, you currently cannot be in two places at once! That means, as both a responsible parent and employee, you owe it to everyone you care about to build support systems so that the world does not collapse if you are not available.

Dr. Ali Griffith, author of Au-Mazing Gift: A Journey to Autism Acceptance, says that parents of children with autism often think they are alone. "Let people know about your child's exceptional needs so that you can create a really solid system," says Ali. "Build a network of people you can call on."

My top tip is to make a little bit of time each day that is just for you
- AuKids reader Carole Christian

Tip 1: Build in flexibility

Not every field has room for flexibility at work. But for some, it may simply be a matter of courageously asking your employer for what your family needs. If you are a high performer, it is reasonable to negotiate for what would propel you towards further success.

Be careful not to broach your request as a personal favour from your boss. Instead, approach the conversation as a business decision. That means setting up a meeting in advance and thinking through how your request for flexibility will help your boss achieve their business goals. If they seem reluctant, ask them to consider



ONE IN, ONE OUT: If you work shifts to keep the home routine going, it's vital you build in 'you' time together

This requires planning and delegation. For example, can you teach your child's teacher what the signs of an impending meltdown are and some ways to prevent it? Can you create a cheat sheet manual for your colleagues about each client in case you are pulled away unexpectedly? Can you ask your spouse to fold the washing so that you can catch up on work e-mails after your child goes to bed?

By thinking ahead and planning, you can easily prevent or neutralise circumstances that might pull you in two directions. Also, there is an upside of impressing your colleagues with your foresight and commitment to work.

Tip 3: Know your resources – and use them!

"Take time to identify all of your resources!" says Dr. Holly Sawyer. She is a counsellor at Life First Therapy and mother of an 11-year old on the spectrum. As a parent of a child with a disability, you are likely to have access to a range of services which may include respite, nursing, developmental services, specialist daycare or school, or financial support. The specifics will, of course, vary a lot depending on where you live and your particular family situation. However, it is worth researching what is available to you so that you and your child can get as much support as your family is entitled to. You may be surprised to find just how many services that you have accidentally left on the table all these years.

For those in the UK, look up your Local Offer online – this is the

I work full time but I have flexi time, this allows me to work from home on Mondays and be at home in the mornings without the pressure of getting to work at 8:30am.
– AuKids reader Kerri Marie

council's list of services that are available in the area for families with disabilities.

Tip 4: Tout your new skills

Special needs parents often apologize for the ways that their atypical parenting has made work more challenging, but they forget to take stock of how they have sharpened their professional skills. All of the advocacy work you are doing at the school and in specialist settings may help you become a *more* adept professional - not less.

As Heather puts it: "I have improved my executive function skills so much because of my son's disability. Before he was born, I struggled with organization and time management and this held me back," she says. "Now, armed with my new Ninja time-management skills, it's so much easier for me. You have to take what seems like a setback and use it to propel yourself to the next level".

Tip 5: Stay inspired

When it comes to blazing your trail, it is immeasurably helpful to find similar pioneers. That is why I strongly suggest finding at least one other professional special needs parent that is further along with the journey than you to offer guidance. This mentor doesn't need to be in

the same industry, career track or even have a child with a similar diagnosis. He or she just needs to be willing to help you brainstorm solutions to problems and give you encouragement that it can be done.

Dr. Sawyer says that finding a way to balance your career with care-giving is absolutely possible. "It can be done but takes a mindset shift. Don't give up," she urges.

Our most important thing is the routine. Whatever is going on, our childcare times and places don't change. That's not always easy to achieve, but the chaos at home if the routine is messed with is worse
– AuKids reader Ruth Mary

Tips From our Readers

Thank you to these readers for contributing their thoughts: Hannah Pilcher, Carole Christian, Jennie Deus, Lorraine Young, Ruth Mary, Rachel Wood, Jennifer Furlong, Gemma Adele, Jo Garner, Laura Hawcroft, Gynaika King, Kate Diaz, Kerri Marie, Jo Sandy and Rebecca Staff.

- Many of our readers have flexible employers who are prepared to offer flexible hours.
- Some found that one partner working from home was the best option.
- Others found that both partners working shift systems meant someone was always at home before and after school.
- Switching from full-time work to a freelance version of the same job is a flexible option.
- One reader advised to check your carer policy at work, it could support you.
- Some readers employ Personal Assistants through Direct Payments to help after school and during school holidays.
- Another reader builds in some flexible holidays for emergencies
- Most agree to stick solidly to the week's routine, whoever is taking care of the children.



- All were super-organised, preparing uniforms and bags the evening before and laying the breakfast table the night before, as well as batch cooking at weekends.

keep organised!

YOUR RIGHTS: Did you know that if you've worked with the same employer for 12 months and are responsible for a child under 18, you are entitled to 18 weeks leave per child, unpaid? Carers UK has published an important fact sheet on your rights at work, plus other useful info, at www.carersuk.org/help-and-advice/work-and-career/other-rights-at-work

If you Stay at Home...

Caring for children is a full-time job in itself. You may not find it possible or desirable to return to work. If you're in this position, make sure you have some head space just for you and that you hold on tightly to your hobbies and your friends so that you don't lose your sense of self.



The Last Word

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

Back to the Good Old Days

At the tender age of just 15, it has always amused me that Bobby is so keen on being nostalgic. "Ah, 2009, that was a good year..." he'll say, as if he's gazing into the last century like some old bloke reliving the pre-war years.

Despite him following all the usual age-appropriate interests, Bobby also has a penchant for watching old re-runs of Numberjacks (a past 'special interest') and Thomas the Tank Engine (also a past 'special interest'). So when Alec started to do the same, searching for old episodes of the Shiny Show on his iPad, I realised that my kids rely on the past to keep them anchored and secure in the present.

It's actually quite useful that I've been able to chat to Bobby about this, otherwise perhaps I'd worry that his non-verbal brother was going 'backwards' by looking at TV shows for toddlers. "No," explains Bobby. "He's just being nostalgic. He likes it being there. Sometimes we have to hold onto good things in the past rather than letting them go. It means not having to deal with change or anything - just being in your own time".

I guess that's why the Maori word for autism is Takiwātanga, meaning 'in his/her own time and space'.

Tim acknowledged the same thing when we were talking about his interest in old postcards. "The past doesn't move, it's always there, it's comforting," he says.

When you think about it, for a mind that struggles to be flexible and cope with the ever-changing present and the vague abstracts of the future, it stands to reason that the past should be a comfort.

With both our boys, I've found that they may be engaged in something new for a while and then will suddenly 'check in' with the past. Alec will start searching for toys that he used to play with on You Tube, watching them being demonstrated. It makes it incredibly difficult to choose what to throw away. I know I'm not alone here! Charity shops do well out of me.

Those of us who grew up in the Seventies used to enjoy a playground game called Acky 1, 2, 3. It was similar to hide and seek, only the person doing the searching had to race back to a starting post and tap it, shouting 'Acky 1, 2, 3!' in order to 'catch' a person. I've often thought that Bobby and Alec are playing out a version of Acky 1, 2, 3 in real life. They'll venture so far, and then have to touch the 'starting post' before exploring any further, just to orientate themselves.

So, it turns out that indulging in a bit of nostalgia isn't just a quaint pastime. It's yet another clever coping mechanism, a cloak of comfort. It's worth thinking about this before worrying about a person's cognitive abilities. Children with autism may well outgrow certain interests, but it doesn't mean that they'll never revisit them.

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