



Aukids®

Issue 48
Summer 2020

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For Parents and Carers of Children with Autism Spectrum Conditions



Memorable Moments
Readers share their
lockdown stories

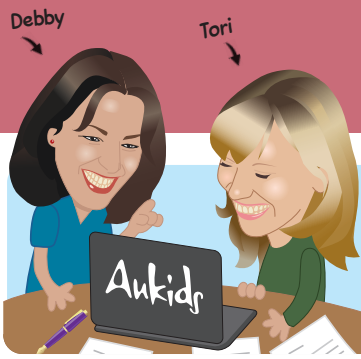


OK Computer?
The pros and cons
of gaming time



Fast Forward
Track three
children's progress
over SEVEN years!





Letter from the Editors

Welcome to Issue 48!

There's been a mixed reaction to lockdown from our readers. Some of you have active kids who rely on regular leisure club visits to divert their energy. This has been especially hard. We hope that by this month you will have a little respite and the AuKids team sends you a virtual hug for what you've managed to achieve so far.

For others, lockdown has been a surprise. Without the pressures of school, and given their own space and time, some kids have come into their own and developed their interests. (By the way, the Maori word for Autism is Takiwātanga – 'in their own space and time' 😊).

Professionals reading this - you've been trying to carry out your usual work under near impossible circumstances and we owe you a massive thank you.

I guess we've all learnt something, even if it's that the limits of our endurance were far broader than we thought!

We hope this issue provides some good company for you if you've

been missing your usual support network.

A few thank-yous:

HUGE thanks to Forever Manchester. Without our usual fundraising events, their £1,000 grant has helped to pay for this issue. Look up www.forevermanchester.com to find out more.



Thanks also to 12 year-old Sol Tibenham. Debby wrote a small story last month called *My Mummy's Brain*, written to give co-editor Tori

five minutes' peace while looking after her four year-old son Remy. Tori posted it (and a spoof version) on Facebook and both became very popular. We wanted to make personalised versions available, so Sol obliged with some fantastic illustrations. You can download both versions under the Books section of www.aukids.co.uk –

and email us if you'd like us to personalise it (aukidsmag@gmail.com). We're working on more of these stories.

A quick reminder:

AuKids will remain in print until January 2021 (Issue 50). After that, our full archive will be available to search and download any time you want it at www.aukids.co.uk but no further issues will be published. Our Facebook site will remain in place.

If you're a current subscriber, you don't have to do anything. We'll contact you with a voucher to spend on past print issues if your existing subscription runs over Issue 50. If your agreement is automatic via PayPal, don't worry we will cancel it after renewal.

If your subscription is just annual (not automatic) and due to renew this issue, it's easier than ever – you'll only be charged £8.00 for the remaining issues left to run. Just go to www.aukids.co.uk/renew

If you'd like more detail on any of this, go to www.aukids.co.uk/the-magazine and click on 'Future'. Our article on what happens in 2021 from Issue 47 is reproduced here in full.

KIDS' PRIZE!

Our *Ice Cream Sundae Guide to Autism* came out in June! We have three copies of it to give away.

Just tell us where there's an ice cream sundae hidden in this issue. Send your answer to aukidsmag@gmail.com no later than August 31st 2020 with 'ice cream' in the subject header. Winners will be chosen at random. No cash alternative. Good luck!



Tori & Debby

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.

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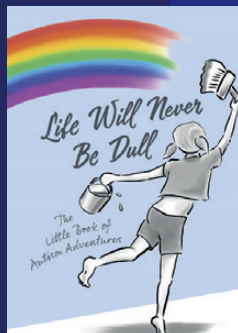
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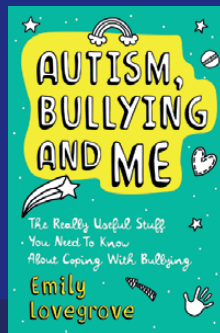


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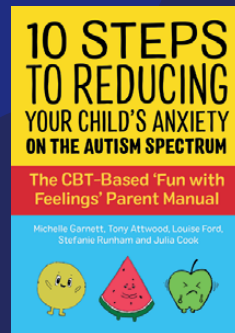
For parents, "A sense of humour definitely helps, as will sleep, and did I mention wine?" A light-hearted, sincere look at life with an autistic child



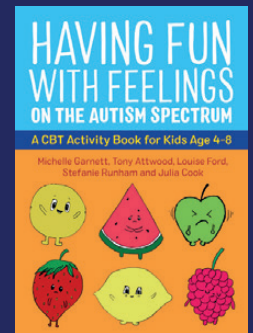
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Make Sense of Summer

With extra restrictions this summer, larking about can be as beneficial to your child as any formal therapy.

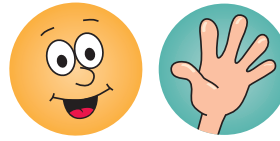
Most children with autism have sensory processing difficulties to one extent or another. This means that the 'channels' through which they receive input from

the main senses can be extra or under sensitive.

If you think that your child may be experiencing sensory integration difficulties, ask your paediatrician for a referral to an occupational therapist.

For this feature, our own speech and language therapist Tori Houghton has teamed up with occupational therapist Tina Wood to offer ideas that can benefit communication as well as sensory integration.

Our smiley face symbol refers to communication benefits, and the hand refers to sensory integration.



1. Going Underground

Garden obstacle courses are great for sensory integration work. Include crawling under heavy mats/blankets for **deep pressure (a)** and crawling over partially filled airbeds for **vestibular (e)** input.

Encourage your child to follow instructions and take turns.



5. Splish, Splash

Modify water play to your child's preferences - carrying heavy water bombs can help to increase **heavy work (c)** if you can cope with the mess! By adding objects/toys to the paddling pool, sorting and matching games can be played.

See if you can predict which toys will sink and which ones will float! Just saying the words "sink?" or "float?" over and over again whilst you're both focusing on the activity will help their language. This is a fun way of your child engaging others and making choices.

8. Space Cowboy

Space Hoppers provide excellent **proprioceptive (b)** and **vestibular (e)** input.

See if you can take turns bouncing on a Space Hopper, count how many bounces before you fall off, or just say "bounce, bounce!" over and over again to reinforce learning language whilst having fun.



9. Walk On the Wild Side

Even simple walks can provide opportunities for good vestibular input and can also provide proprioceptive input if you encourage your child to wear a rucksack. The more resistance under foot, the heavier the work (e.g. wading in water provides great resistance and is excellent heavy work).

Label the things that they find interesting when you go out for a walk using language mapping. Rather than showing them things, comment on what they choose to focus on. That way the language you use is more likely to stick. E.g. "Feather! Soft feather."



2. Circle in the Sand

You can use play sand at home. If your child is sensitive to touch, grade the amount of sand they have to touch (perhaps even start by using a spade). Encourage the experience of touching both wet and dry sand to desensitise them. Hide toys in sand to provide opportunities for commenting and to build visual and tactile discrimination skills.

Build sandcastles and mud pies and introduce words such as scoop, pat, fill and crash. Activities like this are useful for hearing the same words over and over. They are also opportunities to practise counting.

3. Smooth Operator

If your child enjoys them, tactile activities such as rubbing lotion into each other's hands or feet can help to develop **proprioceptive (b)** awareness.

It also provides a shared focus for joint attention and language opportunities. Name body parts as you rub sun lotion in. Pause and see if they can point to any spontaneously - take your time!

4. Blowin' in the Wind

Blowing bubbles is fab for providing opportunities for bi-lateral hand/eye co-ordination if catching them!

Blowing bubbles also helps to develop the **oromotor (d)** skills required for speech development.

6. Sultans of Swing

The linear movement a swing provides can be calming for the nervous system as well as providing a regulating rhythm. Pulling on a rope that the adult holds whilst swinging, if they can manage to stay on, increases resistance and is good heavy work. Otherwise swinging their own legs is still good for sensory integration.

Swings are great activities for helping them to request "more" verbally, with **PECS (g)** or through sign language.



7. Sign Your Name

Large chalks on outdoor surfaces give increased resistance and therefore heavy work for the body. It's also a fun way of practising writing patterns as is writing with hands/fingers in sand.

As with all the games, this gives opportunities for **language mapping (f)**.

The Science Bit

USEFUL TERMS

With the right amount of sensory input our bodies feel calm, alert and ready to tackle daily challenges.

a. Deep pressure input by using something heavy or hugging/squashing games or firm massage, can be calming for a child who swings between being over and under-active. When done correctly, over time it can help to create an optimum state of alertness.

b. Proprioception is the sense of knowing where parts of our body are (without vision).

c. 'Heavy work' refers to proprioceptive input - our brains register it when we use our muscles and joints. So rather than just running about, games involving pushing (trucks/carts etc), pulling (tug o war), wheelbarrow walks and other types of resistance 'work' can help organise the brain's proprioceptive system and calm the nervous system as a whole.

d. Oromotor refers to the brain's pathways that control the speech muscles.

e. The **vestibular** system helps us to maintain balance and move through space by sending information to the brain.

f. Language mapping is when you provide a simple commentary on your child's play. "The train's going **up** the hill! The train's going **down** the hill!" If you do this constantly whilst watching them, it has several benefits. They know that you find their play important without having to interfere, and are more likely to want you to join in. You're also 'modelling' the correct words repetitively. The more you say the same word, (however dull that seems) the more likely they are to learn it.

g. PECS is the Picture Exchange Communication System: Children use symbols or pictures to request preferred objects or activities. It's great to develop this in non-verbal children because it gets them used to initiating conversation themselves (non-verbal children can become quite passive communicators if not encouraged to tell others their needs). Highly motivating activities can provide opportunities for your child to develop the PECS system. So have a photo of sand and the paddling pool at the ready for them to choose from.

USEFUL READING

The Out of Sync Child - Recognizing and Coping with Sensory Processing Disorder by Carol Stock Kranowitz, published by Perigee. ISBN 9780399531651
The Out of Sync Child has Fun - Activities for Kids with Sensory Processing Disorder, by Carol Stock Kranowitz, published by Perigee. ISBN 9780399532719
Motivate to Communicate - 300 Games and Activities for Your Child with Autism, by Simone Griffin and Dianne Sandler, published by Jessica Kingsley. ISBN 9781849050418

Letters from Lockdown

Lockdown has been hard for all of us, but there have been some positive stories to come out of this, too. Here's some to make you smile.

Dear AuKids,

I'm a photography student with an autistic son. To continue with my studies during lockdown, I decided to base my assignment on the challenges of coping with lockdown with a non-verbal autistic child.

My early photographs show William looking upset, confused and even angry that his whole world had been turned upside down. He had been missing his friends, school, family and the play park.

But on this particular day, I glanced at him and noticed he appeared to be analysing the situation and thinking it all through. I had been trying my best to console and distract him by playing skittles in the garden with lots of intensive interaction, and he'd been laughing with excitement and joy. During this rare moment of still, Will seemed to be slowly accepting our new situation.

It was at this point I realised how adaptable and emotionally strong he is. I cannot imagine doing all this and not understanding why, and yet he's taken it in his stride and makes the most of every day with a big smile on his face! With everything we've had to endure, I would never have imagined a child with classic autism would have coped without daily meltdowns, but he's proved me wrong.

Because of this I am already starting to expand my own expectations from him, encouraging more speech and independence. Our Kids are not be underestimated and I'm so proud of how we're coping through such a difficult time.

Best wishes
Julie Beddow



Thinking it through

AuKids replies:

We were really touched with this letter, Julie and it echoes many of our readers' feelings. Thank-you for this and your beautiful photograph.

Dear AuKids

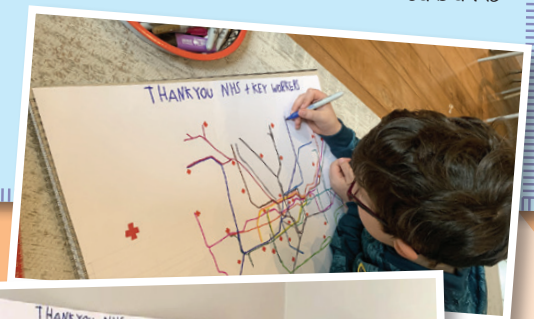
Firstly, thank you for starting this magazine. I was at a loss when we first received our diagnosis five years ago. Discovering AuKids, the UK network of parents and support and so many personal stories as well as the professional advice has been life changing. Fast forward five years and we are in a very different place. And now I'm helping families in the South West of England and connected to incredible support groups. Debby - you kindly sent us your book at one point. Bible!

At this time, it's been an absolute blessing to see how my little boy Romeo (who has autism including sensory processing disorder and is dyspraxic) - approaches education. I've been able to see first-hand the challenges but also to realise that actually all of his specialist interests are so fundamental to his learning and such a gift. By allowing him the space to follow these, amazing things happen.

Romeo has been hand drawing Tube and rail maps from memory since the age of four and during this period he wanted to thank the NHS so decided to combine his love of the Tube and use Google maps to find the central London hospitals and nearest stations. Romeo's map was shared on social media by Transport for London...we've had the most wonderful messages from around the world. A great reminder for Romeo that being neurodiverse is a gift!

(Romeo told me the other day that Isaac Newton and Shakespeare's greatest discoveries and works came during the plague lockdown when universities and theatres were closed...made me laugh. Definitely one for all to remember!)

From Rebecca Da Re



Remember the lovely James who graced the cover of Issue 41 with his sister Yasmin? He's drawn us a fabulous pic to celebrate Autism Awareness Day!

Well done James - awesome work!

Dear AuKids

My son Christopher loves birds and we have encouraged him to try and spot birds in the garden, particularly during lockdown. I came across a bird box and camera on Etsy with a craftsman named Kris under company name KrispyStudio.

I mentioned Christopher loved Angry Birds and happened to have autism. Kris then sent me examples of ways he could incorporate, at no extra cost, the Angry Birds logo onto the box. Christopher was able to then see the development of the box and feel like he had a part in it being created.

The camera is great and now we keep checking for birds nesting - it was £60 for a camera and box or £35 just the box. It was such a lovely gesture and has made Christopher really happy as well as extending his interests.

You can find Kris's work at www.krispy.studio

From Julie and Christopher



Our Facebook Page Has Been Pinging with Positives...!

This lockdown has meant one of my boys got to watch his cat give birth and he watched You Tube videos on how to help her and make sure the kittens were correctly cared for and he's doing a great job! - Jan Fong

I've learnt that our seven year-old is learning so much more himself than he has been at school this year. The research he's doing online himself means he's become a whizz at telling you the designs of the flags of the world and he's fascinated by the coronavirus stats; if you ask him about any country, he'll tell you where they are in their pandemic journey. - Leah Taylor

I've learned that given the extra time and quiet my boy can achieve so much more than he expected of himself. His handwriting has become consistently legible and he can now tie shoelaces - Jennifer Stead

I've learnt to not put too many demands on my son during this uncertain time and give him his own space. He just loves rainbows and getting him out for a walk has been so much easier as we're always counting rainbows in people's windows - Paula McClinton

I'm grateful that my boys were already experts in social isolation - 'Stay at home' has always been their idea of a dream holiday! - Helen Trim

I've learnt that my daughter has so much more capacity to do new things when not in school. She has even started her own autism project ZAP Advocacy and is working with various charities and CICs - Nic King

Without the pressure of expectations to be somewhere, my daughter's so much happier. She's exploring new things, trying new goods, happy to engage in life skills and offering to help around the house. Whilst life has slowed around us, she has found her happiness. - Colette Nuttall



Dear AuKids

My son Jacob, age 13, came home from a walk to find two out of three of our cats on his bed. He has been out of school since January (needs not met) and was just about to start a new mainstream. He has coped well but so frustrated because he was actually looking forward to starting school even though anxious about it.

He is also a massive Liverpool fan and has had to cope with the football season coming to a sudden halt. He has dreamt of seeing Liverpool lift the Premier League trophy for years and has missed out on going to his first ever football match at Anfield, as he was going to the legends match which was postponed.

Anyway, the cats Tibby (ginger) and Snowball have really helped him to cope with everything as has our now retired autism assistance dog.

From Ruth Watts

Cover Star

Seven years ago, Phoebe was our little cover star. This issue, she's back on our cover as we celebrate the progress of a group of children seven years on. See pages 14-15.

Phoebe says:

Age 10

I have The special powers of Autism

Where I live I live in Stockport with my family

School Lisburne School

I love Swimming, watching my DVDs in bed at bedtime, riding my bike (I have just learned how to ride without stabilisers), playing with my Baby Alive dolls and my iPad

I hate Coca-Cola, Lemonade, Peas and Broccoli

Me in three words Cheeky, funny and beautiful

If I were Prime Minister I would play with my friends everyday



Then...



Now!

The A Word: Your Verdict

The BBC drama with an autistic youngster at its centre is now into its third series. Some of us are fans, some aren't. What did our readers make of it? Here are just some of the comments we received.



Personally, think this has been their best season yet. I love that there are so many different characters, each with their own issues and it doesn't solely focus on ASD. - Lizann

Agree with other readers about the lack of Social Stories, I wonder why the NAS or the school they're working with didn't suggest that? - Sam

Does Joe never have a full-on meltdown? It's textbook autism, not the autism that people live with day in day out. - Kelly

I think it's showing the struggles in the most positive way along with solutions. If only it was that simple and easy to get support. It's a humble watch as it's very much a mirror of my life apart from the separation. - Katrina

I'd rather see an autistic child in a mainstream programme, I applaud the BBC for their inclusion of the lad with DS as a regular cast member. But until that time comes, series like The A Word are good for raising awareness. You just have to suspend disbelief at the speed with which problems are solved. Oh, and the Mum is really annoying. She doesn't seem to understand Joe at all. - Laura

I have a child with autism and also a child with Down's Syndrome and I have thoroughly enjoyed this series! It has made me laugh and cry and I have been able to closely identify with the characters. - Michelle

Could definitely relate to the anxiety and uncertainty around moving home, dealing with parental separation. Lots of big themes in the first episode but it's the small comments that catch you unaware and really hit home, like 'When you have this kind of child you're used to feeling like a failure' -. Cracking soundtrack! - Clare

To be honest I have found it uncomfortable to watch so far and thus switched over. They have portrayed Joe and his friend like alien, robot body snatchers. I have met and supported autistic children who fall at various places on the spectrum. I have never met any autistic people so devoid of personality. I feel the portrayal was more in line with Rainman. - Katherine

A lovely programme, but I do want to slap the parents sometimes! Also, Joe is generally pretty calm and easily placated. If people watch it and think all autistic kids are like Joe they have a big surprise in store! - Nicola

I really like The A Word because it portrays really well the negatives and positives of autism and how it affects the whole family. But also there are storylines in it that have nothing to do with autism and just portrays everyday life for some... and I also like the humour - Sarah

The getting used to feeling like a failure comment really struck home. - Michele

I would of liked to see bits more on education, the struggles in education, EHCPs etc... - Donna

I love it. Every time it absolutely nails me with one thing that could be tiny, but has me in tears as it's exactly how I feel about our situation. - Glen

Haven't watched the recent series after I was majorly put off in the first series by the depiction of speech and language therapists! That isn't how we work! - Ali

I loved the moment when Paul went and rolled up his trousers and put his feet in the water; to look over and see Joe doing the same. A really lovely moment after seeing Paul almost struggle with guilt after sitting with Alfie talking football. As for the last scene that episode, that brought tears to my eyes - just shows that we do have those moments when things just click. - Sarah

My own personal opinion is that I do not want to watch it when you live with it and more every day. Just my own thoughts, not burying my head in the sand. - Bernard

It's been absolutely fantastic. Great acting. Show helped son, 18, a lot. - Jean

I don't think it portrays a true representation of what it is like to have and live with an autistic child. My experience is nothing like it. - Majo

It absorbs me every week. The complexity of everyone's lives! I know people criticize it for 'not getting it right', but there are so many real glimpses of what life can be like for some families with a child with ASD, or another disability. I love Ralph's wit! I hang onto his lines, waiting for the killer punchline! - Alison

In the first episode, was screaming for them to use a visual for the changes! - Beccy

It's great to see a drama that has more than one character with a disability and portrays the everyday ups and downs of family life including the advantages, as well as the disadvantages of having autistic siblings, children, grandchildren and colleagues. All set to a great soundtrack with beautiful scenery. - Sally

I think the show is a brilliant representation of what our world's like, be it with a child who has Down's Syndrome or autism. It's been lovely to see how the parents have adapted to Joe's world. - Sophia

The characters with autism are so deadpan and monotone. They aren't funny. And the parents are really annoying! As my daughter said, it isn't written by anyone with autism. We are lively and witty at times too. It really annoyed me when one character wanted to join the army and someone said 'Oh so and so waited at the wrong bus stop 5 years in a row and is now in charge of weapons'. As if we are thick! Why couldn't someone with autism be in the army? I inherited my autism from my Dad and he was in the army. He was a good soldier. - Becky

Readers Recommend YouTube channels

Slapstick

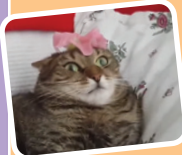
Annoying Orange:

Does what it says on the tin. Don't say we didn't warn you. He is VERY annoying. Note this isn't suitable for very young children, there's rather an overabundance of veg and fruit being horribly murdered. Do watch it first.



Daily Picks and Flicks – Cat Can't Handle Flower:

One of our reader's kids just thinks the whole thing is hysterical and sings the song, too.

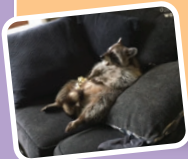


Kyoot: KYOOT believes in random acts of funny, it says. KYOOT believes all people are unicorns! That's where its description stopped making sense. It promises a fun and friendly place to laugh, cringe and connect. Reader Kerry describes it as a 'You've Been Framed' for kids.



Smile More: Family friendly pranks.

Smile More.



The Pet Collective:

Kate's son Daniel loves the slapstick nature of this channel.

Transport

all the STATIONS

All The Stations:

All things railways!



Arriva Bus: Footage of bus routes for vehicle fans.

Geckos Real Vehicles:

Gecko explores a different vehicle in each episode.



Spinning stuff

The SuperFanMan:

A wide variety of videos showcasing electric fans, including; demonstrations of fans, unboxings, in-depth product reviews, restorations, DIY projects, and much more. For the fan fan in your life.



whichwasher2007:

Watch a tumble dryer in action. For tumble dryer fans, obv.



Gaming



Camodo Gaming:

Video games channel.

Cmin2getcha Plays:

Minecraft tutorials with an emphasis on building football stadiums it appears. According to one Judy's son William he explains what he's doing clearly which is why he likes it.



Dan TDM: Famous gaming guru who tests lots of games and doesn't use bad language.



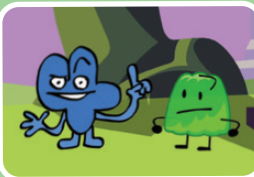
FGTeeV:

Meet FGTeeV Duddy his wife FGTEEV Moomy, their sons Shawn, Chase and Mike and their daughter Lexi. The hyperactive crew of gamers invites you to dive first into their world of gaming and sketch comedy. 'If I hear that man scream one more time I might cry...' says reader Rachel.



Jacknjellify:

Twenty characters battle for a luxurious island in an elimination-centric viewer-voted animated series, including BFDI (Battle for Dream Island), BFDIA (Battle for Dream Island AGAIN), IDFB, and BFB (Battle for B.F.D.I.). We literally have no idea what this is.



Stampylonghead: Different gaming videos including lots of Minecraft.



Creative

JangBricks:

Calm and positive vibes in family-friendly LEGO® set reviews, custom creations and a room-sized LEGO® city and train layout! Speed builds, too.



Squash Clay:

Videos showing Pokémon characters being made from clay. One reader told us her son found it calming.



The Icing Artist:

WOW-worthy desserts with just a few simple tools and ingredients.



Sensory

Experiment versus Everything (EVE):

is surprisingly popular amongst autistic kids who seem to get sensory satisfaction by proxy watching a car running over squashy and crunchy stuff. Not the most environmentally friendly of channels, it did at least have the decency to point out that the crushed eggs were out of date.



Guava Juice:

Guy does everything sensory you wish you could do, like fill a bath full of jelly balls or Skittles sweets. Absolutely insane.



Can't Categorise Because It's So Random

Kids Diana Show: Toys unboxing, Challenge, vlogs, funny playing with water, water toys, surprises, games, entertainment. To be perfectly frank it's clear from the description that English isn't the first language here, so what Diana does is anyone's guess but Glen's son Fred is obsessed.



“My child is into computers and focuses on things he can play by himself. Is this bad for him?”



Tori Houghton

Speech and Language
Therapist, AuKids
co-editor and Director of Time
Specialist Support

Many young people with autism find the 'directness' of face-to-face social interaction and communication difficult. There are so many variable factors to consider in interaction - particularly with non-verbal signals - which people with autism find

confusing. Many people who are considered 'lower functioning' may struggle to develop functional speech because of this reason yet are able to write/type/use pictures effectively to articulate their thoughts and feelings.

The predictability a computer may provide and the lack of complicated non-verbal messages to interpret often make this an effective way of interacting with the world for autistic people.

In this day and age we use a variety of technical means in which to interact with our peers e.g. texting/Facebook. Capitalise on your son's interest and encourage these skills under supervision, in ways which he can use to communicate with others in a non-threatening way.

Many of his peers will be interested in similar games, so use this interest to help develop his conversational skills, first with you, then with siblings and/or peers. The latest computer craze may be an important topic of conversation in which he can be encouraged and supported to discuss with his peers.



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

Socialising is an extremely common characteristic of the Predominant Neurotype (PNT) - and is often deemed highly important and valued. An easy mistake to make is to apply the same value system onto autistic children - whereas, in fact, by definition the autistic child is highly likely to have a very different set of needs when it comes to social interaction - for a whole host of reasons. Sometimes, simply, the child

has no interest in other children - to force the issue in such an instance would be unwarranted and unfair, and is sometimes more a reflection on what other people want rather than what is best for the child. However, it may be that the child has had such bad experiences previously that s/he becomes reticent and withdrawn - this is far more problematic. The critical question I believe is: when on his/her own, is the child content and happy - or lonely and depressed? In the former instance it may well be prudent to allow the child to develop in his/her own time. In the latter, there needs to be some input.

Computers are not necessarily the isolating beasts that they are sometimes made out to be - in fact, in this day and age the online community (including gaming) has its own type of valid socialising which can suit autistic children very well indeed. Using the computer (safely) to engage with others can be one of the most 'autism friendly' ways to develop social interaction; my advice would be to see this as an opportunity rather than a problem.



Mackenzie Whitney

Mackenzie is 31 and lives in Calgary in Canada. He has autism and currently works as a computer software tester for Morgan Stanley.

I work as a software tester and my primary responsibility is to write and conduct tests in order to verify an application's functionality and find errors during development.

If your child's focus comes at the expense of socializing with others consistently, then there is an issue, but I don't think this is an issue with an activity in itself (such as an interest in computers), but rather an issue with scheduling time, which should be a collaborative effort.

I believe part of that schedule should retain periods of 'alone time' as a way to relax away

from social situations that can feel particularly taxing for a person with autism, but one way to encourage socialization and exercise for part of that time is to enrol them in an activity they would enjoy. An example from my childhood was being part of a swim team Monday, Wednesday, and Friday afternoons. I still had my alone time, but it wasn't at the expense of my overall wellness.

I will add that there are several advantages that can come from an interest and use in computers, not only from being fluent in a technical aspect (using office applications, effective online research, coding), but also socially. Social media platforms and forums, for example, can provide an outlet to discuss common interests, share art and writing, or collaborate. Local group meetups and social gatherings can be browsed and scheduled for online. Learning online etiquette is a useful skill for a work environment (text chat rooms, video conferencing).

The list goes on, but in summary, computers should be seen as a resource, and an interest in them fostered, especially when computer fluency is a valuable skill in today's modern world.



Bobby Elley

Bobby Elley is 16 and has autism. He is co-editor Debby Elley's son and is about to go to college to study creative media.

One of my opinions is that computers are a source of control, which is

what autistic people want. With this control they can search for anything they desire, and they'll get it, with no unexpected results. Autistic people prefer things that are exactly what they want.

According to what I've found, autistic people tend to know a lot because of their visual understanding. By being able to process familiar pictures and audio from computers and recall it from memory, they can use pleasurable information and build on it for more complex knowledge – it helps them to understand and make sense of the world.

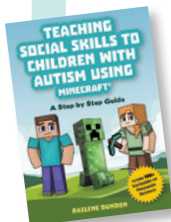
Plus, they tend to like it on their own. Imaginary friends and worlds are predictable. It means we don't have to get bothered by the complexity of social rules that exist in the real world.



Raelene Dundon

Raelene Dundon is a Child Psychologist, speaker, and the author of several books on topics related to autism for both parents and professionals including

Teaching Social Skills to Children with Autism Using Minecraft, A Step by Step Guide. She is also the parent of three children, two of whom are autistic. Look up: raelenedundon.com



With so much media discussion on the effects of 'too much screen time' on children, parents often come to me concerned about their autistic child's interest in computers and gaming and the amount of time they spend playing online.

While it may be a concern if a child is spending time on a computer to the exclusion of all other activity, spending some time doing something they enjoy, including playing computer games and having alone time, are actually important for any child's well-being.

For many of the autistic children I work with, and for my own children, being at school and in other situations requiring prolonged social interaction is exhausting, even if they really enjoy them. Consequently, being able to come home and tune out by doing a favourite activity such as playing games or watching videos on the computer is necessary for their mental health and their ability to function

from day to day. The predictability of computer games and the ability to escape into another world that they can control provides a break from the pressures of everyday life.

While it is important to find a balance between solitary computer time and supporting a child to engage in activities that provide opportunities for forming relationships, social interaction, and physical activity, it is also important to consider the child's individual interests, motivations and needs. Some autistic children may tolerate social interaction but prefer to be on their own when they have a choice, and that is okay. If they are happy and content with their own company, they should not be forced to spend extended time in social situations just because others do.

On the other hand, if a child is interested in having friends and wants to engage socially but avoids social interaction due to negative experiences or anxiety, spending a lot of time on computers on their own could get in the way of them developing positive relationships with peers.

The great thing about computer games is that they are often an age appropriate activity and can provide a great avenue for social interaction around a common interest. Therefore, encouraging a child who wants to engage with peers to play computer games with others, can be a fantastic way of reducing a child's feelings of isolation and supporting them to develop friendships and have social success.

Ultimately, I think honouring a child's individual interests and needs, and finding a balance between computer time and other activities where appropriate, will provide the best possible environment to support an autistic child's wellbeing and development.

Gamer's Reading Library

You can use any special interest as a 'jumping off point to doing different things and one of them is reading! Most books below are suitable for ages 8-12 depending on reading level.

The Person Controller by David Baddiel is suitable for younger children, with larger type and double line spacing and illustrations throughout by Jim Field. If your child can read Horrid Henry, they'll cope admirably with this. Published by Harper Collins.

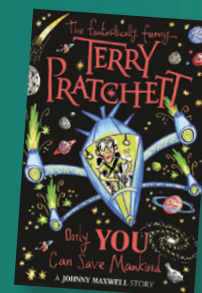


The Gameknight999 Adventures Through Time Box Set: Six Unofficial Minecrafters' Adventures by Mark Cheverton

Gameknight999, a former Minecraft 'griever', gets a big dose of virtual reality when his father's invention teleports him into the game. Not sanctioned by the makers of Minecraft, this is fan fiction at its best. Language good readers age ten and up will understand, no illustrations. Published by Simon and Schuster.

Only You Can Save Mankind

by Terry Pratchett
Meet Johnny Maxwell, a normal boy with the most ordinary life. He loves video games, but one day, after receiving a mysterious message from the last remaining alien spaceship in the game he's playing, his life drastically changes. Published by Penguin.



Hacker by Malorie Blackman

Vicky is the best hacker in the world and when her father is arrested after being accused of stealing money from the bank he works at, she uses her hacking skills to prove his innocence. This is a fantastic read for those with a passion for coding. Published by Penguin.

Ctrl-Z by Andrew Norris

What if your computer took you back to an earlier part of your day when you hit Ctrl-Z? Together with his friend Callum, Alex puts his unique computer to good use, but faces the consequences of going back in time. Published by Penguin.

Monstroso by Charlie Higson

After finding a mysterious file on his dad's computer, Oscar creates Monstroso, a real-life warrior. This warrior is programmed to do anything Oscar asks him to – but soon he realises that his new friend will only ever get him in trouble! Published by Penguin. Suitable for younger readers - funny!



Daniel X: Game Over by James Patterson

Daniel X is one of the greatest superheroes to ever exist and has beaten tonnes of evil-doers. In this book, the alien-hunter must eliminate a pair of shape-shifters who own a famous video-game enterprise. Published by Penguin.

Ready Player One by Ernest Cline (a film was made of the book) – Suitable for older teens with very good reading skills. Set in a dystopian future where the world is a depressing place and virtual reality offers the only escape. Described as 'Willy Wonka meets the Matrix'.

Also look out for many adventures connected with Skylanders, and books written by your child's favourite You Tubers. Search Amazon for writing and spelling books connected with Pokémon and Minecraft.

Disability Living Allowance



Disability Living Allowance is issued by the Department for Work and Pensions and is a weekly allowance that you may be entitled to if you look after a child under 16 with a physical or a mental disability, including autism.

It's not means tested, so it doesn't matter what you earn and you don't necessarily have to have a diagnosis, but it does help! There are two parts to the DLA, a care component and a mobility component. To receive the care component, your child has to take longer performing daily tasks than they would do if they didn't have a disability. The highest rate is currently £89.15 a week, the middle rate is £59.70 and the lowest rate is £23.60, so it's worth applying for.

Even if your child walks fine, an autistic person who has no sense of danger or who doesn't tend to move purposefully may also be eligible for the lower rate of the mobility component, which means an extra £23.60 a week.

There are excellent guidelines on the Government's website and you can apply online. Look up www.gov.uk/disability-living-allowance-children or call the Benefit Enquiry Line freephone on 0800 121 4600. Skybadger is a great source of support for families of disabled children and has links to help you fill in benefit forms at: www.skybadger.co.uk/2017/01/15/dla-for-children/

The Benefit... or the Doubt?

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

Working Tax Credit

If you're claiming disability benefits for your child, you may qualify for extra tax credits. Look up here: www.gov.uk/working-tax-credit



The Blue Badge Scheme

It's often thought that you can only qualify for a Blue Badge, which allows you to park in a disabled space, if you have a physical disability. But certain traits that some autistic children have, such as no sense of danger and dangerous behaviour such as running away, are grounds for an application. Last year, the Blue Badge eligibility rules were changed to reflect the needs of autistic people. You're automatically entitled to a Blue Badge if your child gets the Higher Rate of the mobility component Disability Living Allowance (DLA). You may still get it if your child is vulnerable moving about.



Don't apply for a Blue Badge anywhere other than your council or the government site at www.gov.uk/apply-blue-badge

If you have been awarded the HIGHER rate of the mobility component of your DLA, you are entitled to a refund on your car tax, too.

Carer's Allowance

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

You are eligible for it if you are currently earning less than £128 per week after allowable deductions and it is taxable.

Your caring role must be at least 35 hours per week. You don't have to live with your

child to claim it. Carer's Allowance is currently £67.25 a week.

For further help, look up www.gov.uk/carers-allowance/overview or call 0800 731 0297. The charity Skybadger's helpline is: Telephone: 0800 731 0297. For a form contact the Carer's Allowance Unit on 0845 608 4321. For advice on how to fill it in, contact the Benefit Enquiry Line on 0800 731 0297.



Self Directed Support: Direct Payments/Individual Budgets

Self directed support is a way of giving you control over the help you get for your child by giving you the cash to meet their needs. Direct Payments are an example of this. We've met loads of parents who don't know about them or are too nervous of what it involves to get them. And yet they could make a big difference to you. Direct Payments can be used to help with the cost of respite care, support in the home or a personal assistant to support your child



when you're out and about with the family. A social worker will be able to assess you for them.

As well as good advice from the Direct Payments team in your council, Contact A Family is a great organisation supporting families like yours. For their advice on Direct Payments, look up: www.contact.org.uk/advice-and-support/social-care/how-to-access-services/personal-budgets-and-direct-payments

Wherever you live in the UK, you can call Contact A Family's freephone helpline (Monday-Friday, 9.30am-5pm) on 0808 808 3555, or ask a question by e-mailing helpline@cafamily.org.uk

Other Benefits

Nappies

If your child is over 4, you may be entitled to free nappies from your Primary Care Trust. Your health visitor or GP can put you in touch with a local continence nurse who can help with this. Trusts vary in their eligibility criteria.



Leisure Key Card

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

Disabled Toilet Key

RADAR (Royal Association for Disability and Rehabilitation) runs a National Key Scheme (NKS) to give you access to locked disabled toilets around the country. Just Google 'RADAR key' and you'll easily find one cheaply on the internet, or go to www.ageukincontinence.co.uk

For a great guide to RADAR keys, look at www.bluebadgecompany.co.uk/blog/radar-keys-locked-disabled-toilets-explained



Cinema Pass

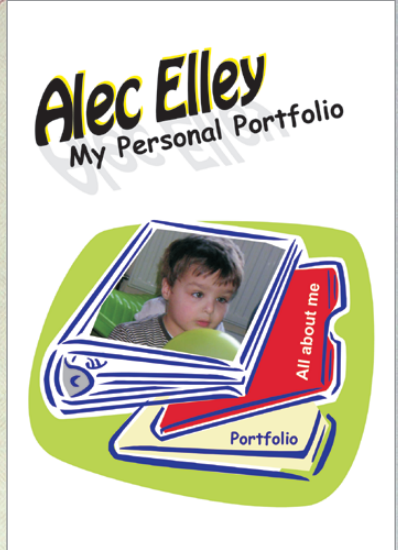
If you are in receipt of the DLA, you can apply for a Cinema Exhibitors' Association Card. For a one-off payment of £6, this gives carers free entry to movies when accompanying their child. Great for those times when you're not sure if they'll hack the full film or not! To apply look up www.ceacard.co.uk or call 01244 526 016 during office hours. You can email info@ceacard.co.uk



FIVE-STEP GUIDE TO MAKING A 'PASSPORT' FOR YOUR CHILD

(not a real one, that would be illegal)

With less preparation time for the new school year given the You Know What restrictions, how about helping your child's teachers out by making a communication passport? Also known as a 'personal portfolio' or 'pen picture', it's a visual guide that gives autistic children a means of sharing their own personal information such as their likes and dislikes. Using one will save you from repeating yourself to everyone who looks after your child. It will also ensure that they all have the same information and a written record that they can reference.



SNIP IT
Passports do not need to be done on the computer! Cut-out pictures with written passports are just as effective.

1 Decide what's inside

Think about the information you would want someone to know if they are meeting your child for the first time – the sort of information you would pass on to someone looking after them. Think about how your child would describe their difficulties and write the information from your child's perspective to help an adult get to know them. e.g. 'I really like watching *In the Night Garden* and Iggle Piggle is my favourite soft toy'.

SHARE IT
Share the Passport with your child, they love to see themselves in print!

WEAR IT
Make it into a book with a ready-made plastic spine from stationery stores and if you can, laminate it for longevity.
<513>

2 Start the passport with an introduction which describes your child's difficulties from their perspective.

E.g *Hi! My name is Joshua and I have autism. This means I find it hard to let people know what I want and how I feel. Even though I don't use words, I do understand simple instructions and I will try and let you know what I want by leading you to it.*

UPDATE IT
An out-of-date passport isn't much use. Make a note of the date that you finished the first version, then update annually.

COPY IT
Keep several copies at home so that you can hand one over at a moment's notice if for instance you have a new babysitter.

3 Answer the following guided questions (choose those which are most appropriate to your child)

- Who do I live with and who else is important to me? (include pets)
- What school do I go to and what activities do I do out of school?
- What are the three things that I like the most – how do you know?
- What are the three things that I really don't like – how do I show this?
- Is there any physical/medical information that people need to know?
- How do I communicate what I want/don't want?
- What's my favourite food and what do I usually drink?
- What food do I not like?
- Is there anything about my behaviour that you would need to know?

SPARE IT
As it's a work in constant progress, don't spend too much money on making it lavish.
ADMITTED 325
EA-AB-10-0066

4 Add photographs and visuals to support the information.

5 Add any important contact numbers towards the back of the booklet.

Useful Resources

Schools:
For mainstream school, you can collaborate with the SENCO to produce an at-a-glance A4 sheet of paper for all teachers. On it, include name, date of birth, access arrangements, a photo, plus these phrases:

- I would like you to know that...
 - This means that...
 - I find it difficult to...
 - It would support me if you could...
 - I will support myself by...
- Add whatever support the child currently receives.
Thanks to Priestnall School Stockport who currently use this idea.

Hospital: The National Autistic Society has produced a wonderful template for you to complete to guide healthcare professionals should your child be admitted to hospital.
www.autism.org.uk/about/health/hospital-passport.aspx



Parenting with Vision!



'Visual support' is the most common aid for children with autism and often recommended to parents by speech and language therapists. Here's a guide on how best to use it.

By *Tori Houghton, speech and language therapist specialising in autism.*

We all depend on visual information. Daily cues such as road signs, labels and logos are powerful navigation tools. As well as words, we communicate using gestures and body language. If we were to find ourselves in a foreign country, we would highly depend on our visual skills – maybe seeking out the familiar golden arches of McDonalds or someone to point the way to our hotel.

The Science Bit

Information comes to us through our senses. For spoken language, we depend on our auditory skills (our hearing).

This complex process involves:

- switching our attention to what we are supposed to be listening to
- filtering out all the background noise
- picking out important words
- decoding the words and making sense out of them

For children on the autism spectrum, there is likely to be a 'breakdown' at one or more of those stages.

They may struggle to know what to attend to and have delayed and slower auditory processing skills. It may also take increased effort on their part to filter out irrelevant background 'noise'. Words are totally abstract and their meaning isn't often obvious. Words are also transient - once said, they quickly disappear.

Vision On!

We may be used to our high dependency on words but anyone who's played charades will agree that it's just as easy to get information across visually.

"Sometimes it's hard for me to understand people directly. I sort of 'translate' what they say into charts, diagrams, maps, and timelines, and I view mental subtitles of what they say - reading the subtitles is a lot easier than listening to the words."
Alexptrans (alias) - adult with autism on Wrong Planet.net

What do we mean by visual support?

'Visual support' simply means using an actual object, photograph, symbol or picture to convey meaning.

Why is it so important?

- It sticks:** There is more time to look, process and interpret.
- Supports expressive language:** It can help the child to use a word that they may not already be familiar with.
- Supports understanding:** It helps children to structure and organise their day.
- Helps with requests:** Pre-verbal children can use visual support to ask for things.
- Supports social skills:** Visual support in the form of words, stories, cartoons or drawings can also help to explain social situations. They can

help slow down and re-create an event that has taken place quickly.

- Supports language development:** Children who are able to build simple sentences using symbols tend to 'hit the ground running' when they develop speech.

What type do I use?

Symbolic language ranges from the most tangible, such as an actual object, to more complex visuals such as using the written word to reinforce an idea. What you use depends on your child's needs and ability as well as the situation.

Cartoons are great for a quick chat about a situation that has just happened. Written words are sometimes better when situations need to be explained in advance.

For a pre-verbal child, support can take the form of simple pictures or symbols.

How does it work?

Real object: "I use Felicity's cup to let her know that I'm offering her a drink."

Objects of reference: "When I show Toby the car keys, he knows that we are going out for a drive."

Photographs: "When we are going out, I show Martin a photo of who we are going to see and he holds this for the journey, which seems to give him comfort."

Symbols: "We use colour symbols to offer Chloe choices in what she wants to drink."

Line Drawings: "I draw two things that we are going to do and tell Davey - 'First shopping - then McDonalds'".

Sign Language: "I use Makaton signing with Ella around simple every day routines. She does look at me when I do this even if she is not copying me yet".

Written Word: "When I go out with Jake, we write a list of what we are going to do from getting into the car to getting home again. It reassures him and we have less frequent tantrums."

Not For You? Yes it is!

Problem: I don't have the complicated symbol package.

Answer: Easy - use photographs or Google images.

Problem: I'm not very good on the computer.

Answer: Use packets from favourite foods, photos from your phone or DVD covers.

Problem: I don't want to use different symbols from the ones at school.

Answer: Good thinking - ask school for copies of the symbols they use.

Problem: I don't know any Makaton signs

Answer: You can pick them up from CBeebies' Something Special and in some areas Makaton courses are run free of charge for parents. Ask your speech therapist to find out more.

Problem: It's a bit fiddly and I'm always losing symbols

Answer: Have a key-ring made with common symbols or use blank symbols and a marker pen.

Problem: I don't want them to be doing 'school' things at home, they need to relax.

Answer: You wouldn't remove a ramp for a wheelchair at home because it was more relaxing. Auditory processing difficulties don't just happen at school. Visual support is a requirement wherever you are, if you want your child to be able to communicate and ease their frustration.

"I think in pictures. Words are like a second language to me. I translate both spoken and written words into full-color movies, complete with sound, which run like a VCR tape in my head. When somebody speaks to me, his words are instantly translated into pictures."

Temple Grandin, author and adult with autism.

Finding My Way

TIM TUFF has autism, dyspraxia and dyslexia. Having endured a tough school life during the 70s, Tim's determination nevertheless led him to find regular employment. More than ten years ago, he became a volunteer for AuKids magazine. These days, he volunteers for a number of organisations as well as giving talks. One of the things that has changed most about Tim over the last decade is his ability to hold a conversation. We had a chat with him about what had changed, and why.

Interview by Debby Elley



"In the past, I didn't listen to other people, primarily because I didn't think they'd understand me and also they didn't have anything of interest to talk to me about. I didn't know what they wanted to talk about, so we were in like a stalemate," says Tim.

We reflect together how difficult it can be to strike up a conversation when your focus is entirely on things, rather than people or situations. This means that whoever you talk to has to be interested in the same things to make those interactions work.

"Some autistics will tell you what they're interested in and reel it off, others aren't like that, they just keep it quiet. I'm the person who always has to talk about what I like! If someone didn't seem interested, I'd just think 'What's the point in talking to them?'"

Tim's early conversation skills developed through some understanding family members.

"My mum has always been there to listen to what I have to say, even if she didn't always like the same things as me. My grandparents always showed a good interest in the things that I had. When my brothers and sisters used to play out, my grandad would show me on a map the places where he'd been and how he'd travelled – by bus or train. I learnt about places through that".

Other people's enthusiasm played a big part in Tim's ability to learn. This isn't the same for all autistic people – some can get overwhelmed by highly excitable tones.

"Sometimes people think I've known about something for

a long time. I haven't, it's just that I've had a conversation with one person. Because they're enthusiastic about it, the enthusiasm rubs off on me.

"At school the teachers always sounded boring, whereas someone who does it as an interest is enthusiastic and it sounds more like it's from the heart. I can't tell someone is enthusiastic by looking at their face, but I can tell it from their voice. If my grandad had something to show me, he would rush to the bookshelf and grab the map out and enthusiastically point to places. His enthusiasm helped me to learn."

.....

"I can't tell by looking at them if someone's bored. I've had body language training, but the thing is it's so vast. Training doesn't help because I can't read context".

.....

Until ten years ago, Tim's conversation skills were quite limited. Then things changed. Having mixed with family and autistic people nearly all his adult life, he started to volunteer for autism causes. For the first time in his life, he found himself surrounded by non-autistic adults who understood him. Tim developed something he'd previously lacked – trust. His trust in people had been severely damaged by his school experiences, but now it started to grow again.

The new circles that Tim mixed

in and the autism causes he promoted gave him more confidence to talk to new people and to listen.

"What helped me change the way I listen to people? People now have more of a desire to listen to what I have to say. I'm thinking 'Because they're interested, they'll tell me if they know anything extra...' and so I listen more."

Autistic people know if you're switching off, even if they don't show it – and they switch off in return, becoming less open in social situations.

Once Tim became more engaged in conversations, he began to fine tune his skills.

"When I meet somebody, I try and hold back and listen to what they've got to say before I speak. I've had to learn that. I have also developed a way to shorten the time I talk about things. If I don't get any interest or anyone saying 'that's nice' or something within the first five minutes, I think I'd better turn off.

"I can't tell by looking at them if someone's bored. I've had body language training, but the thing is it's so vast. Training doesn't help because I can't read context.

"In one way, I'd like people to tell me that they were bored of what we were talking about. But people don't do that. I'd prefer sometimes if people just said 'Enough of that, let's move on...'"

Other people can make it easier, he says, by taking time to learn about a person's interest, talking to them when they are relaxed, allowing processing time to answer a question and getting

to the point of a conversation quickly.

"If people don't get to the point of something within the first minute, I've switched off completely. My mind is thinking 'What is the conversation for? Where is it going?' I need to know the point of the conversation at the beginning."

For Tim, talking to others in an understanding context has resulted in a reduced fear of new situations.

"I don't feel as anxious as I used to because I've learnt that not everyone is autistic, but some people have quirks and stuff like that...which I won't say that I like exactly, but sometimes it's quite unusual and that makes me feel more relaxed. At one time I didn't notice it as much, but now I can notice different people's quirks and their little habits as they're talking to me. It makes me feel like I'm not alone in being unusual.

"I suppose as I've mixed in other groups, I've started to spot more about other people. When I'm doing autism training, people are all different. I notice how they act when they come in the room and actually it surprises you.

"At one time I would have thought 'This is 16 people' but now I think 'This is 16 individuals'. They're not the same. Their reactions to what I say are different. The way they interpret what I say is different. It's surprised me, at one point I thought people who weren't autistic were automatically the same".

That's only what 'neurotypicals' have for a long time assumed about autistic people, eh Tim?

Fast Forward Seven Years



When you experience every day with a child, small steps forward can seem almost imperceptible. Sometimes it's only when you look back that you realise how far they've come. In 2013, we asked a group of parents what they'd like their children to master over the following year. Twelve months later, we reported again. Seven years on, we tracked them down once more.

Ted Humphreys

January 2013, Age 5



When we first spoke to mum Ruth about Ted, she said: "I'd like him to accept a food that isn't a Cheerio or piece of dry toast! He can currently say numbers 1-12 in order and say 'squirrel' - I'd love him to be able to say a word that he can use to his advantage! To improve on PECS* (Picture Exchange Card System) - he's just at the first stage".

As well as communication, independence was a priority: "To put his own shoes on; he attempts to now and as getting shoes is his way of saying 'I fancy a walk outside now' - I'm sure he'll master that one. I'd also like him to appreciate the benefits of sleep more, although that's purely for selfish reasons!"

When AuKids last caught up with him in 2014 at the age of 7, Ted would eat toast with butter and Marmite, but expanding his dietary repertoire was still a challenge. As for PECS, he flew through all the stages and having mastered it fully, had learnt to say 'I want' and vocalise some other key phrases.

July 2020, Age 11

By Ruth Humphreys, Ted's mum

Things have really changed. We don't use PECS anymore. He knows now that words are the fastest way to get what he wants. He can say short sentences and get his everyday needs met with these, but he will use as little as he can



These days, Ted loves numberplates.

get away with unless he's motivated. If he's highly motivated, his language and communication will be outstanding and he'll use every trick in his book to get his point across.

Ted loves to do his own commentaries, (he's got this from YouTube). He'll provide commentary while going in lifts, when I'm cooking a meal or when we shop. It gives strangers the impression that he has more understanding than he does; they'll ask him questions to which they'll get absolutely no response...

In the last year Ted has started to use 'I hear' and 'I see' and he's able to talk about what happened yesterday or what will happen on a future date at a basic level. In the past, if fun things had happened, they'd stay in the past. Now, we are able to reminisce.

Ted doesn't speak for the sake of it, so when he does talk it's priceless. He has to practise words before he perfects them, pronunciation doesn't come easily. When he finally masters a new word his face lights up.

At nine years old he started to use 'yes' and 'no' in answer to questions. One day his big brother was sitting with him and asked if Ted would like to listen to Havana song, to which Ted replied a very definite 'NO!' We were both stunned but delighted.

These days it's very interesting to see what his choices are. I can ask him now instead of assuming the answer. It's amazing how much information you can get out of someone with

purely 'yes' and 'no' answers!

I do have to frame questions clearly because he is very literal. For instance, if you asked him if he WANTS a wee, he'd say 'No', but rephrase that as 'Do you NEED a wee?' and he'll say 'Yes'.

Ted loves greetings and goodbyes. When saying goodbye to grandparents, if both are around it's 'Goodbye both' and if just one is there it's 'Goodbye single'.

His honest use of language is often amusing. He tells smokers 'Fwoar, very smelly!' and likes to tell checkout assistants 'Thank you and hurry up'.

He can now dress and undress and apart from buttons, he's completely mastered this.

On a recent progress form at school he was asked what he would like to improve. He wrote 'independence'. When asked why, he wrote 'Because buttons!'

Diet has been hard. He's healthy despite only eating beige crispy dry foods, one type of yoghurt, baked beans and Marmite. He has the same foods at the same times every single day.

Until very recently he'd never eaten any fruit or vegetables and has almost a phobic reaction to having them anywhere near him. Today, he took and ate three big pieces of roast chicken and gravy from my plate... Well, he sucked them; he looked confused while he ate it. The big win there is that after years of coaxing and trying to interest him, he finally made a move... A few weeks ago, he tried tiny pieces of grape and apple.

He still doesn't sleep well though and is up every day between 3am and 4am, sometimes earlier. There are loud night-time conversations and sometimes walkabouts. During the night he's not usually unhappy when he's awake, just loud.

It's a bit weird when he's manically laughing, but you get used to it. It's being woken by someone looking right into your face that takes some getting used to!

*PECS - Picture Exchange Communication System commonly used in autism as a visual tool to aid communication. It is a method by which children initiate communication by handing a picture card to an adult. Eventually sentences can be formed using PECS. www.pecs.com

Harry Palmer

January 2013, Age 7

When we first spoke to Harry's mum Alison, she said that she'd like Harry to be dry in the day. She was also keen for him to use colours to comment with PECS and to use a few more words. She wanted him to be able to put his socks and T-shirts on. Plus, she said she'd love him to drink something other than diluted apple juice!



A year on, and by the age of six Harry was dry quite a lot of nights, but not all. He was able to indicate during the day when he needed a change or wanted the toilet. With enthusiasm and encouragement from his parents, he started to drink blackcurrant juice as well as apple.

When Harry was six, his parents had decided that they wouldn't focus on learning colours for PECS but would follow his interests which they felt would be more useful. As soon as he showed an interest in something, it would be added to his PECS book. He started to be able to request multiple things in one go. They then developed his PECS further. If he requested TV, he would choose a PECS card for the programme, then choose which episode from a further sheet.

Harry's biggest success at six was vocalisation. He started to use a few words regularly and appropriately and give the initial sound of the thing he wanted. Alison says they found Talking Tins and a voice changer brilliant in developing the use of his voice.

With assistance, Harry started to dress himself.

July 2020, Age 13

By Alison Palmer, Harry's mum

Harry now uses an app, LAMP Words for Life, on an iPad that is solely used as a communication device. It generates speech and we refer to this as his 'talker'. Harry took to it immediately. We made this our priority. If he says anything at all with it, we continue to drop what we are doing to respond excitedly.



He now answers basic questions, will request things, comment, refuse things and is just starting to ask questions. He strings words together: 'trampoline, garden, please,' and we are working towards full sentences. He has a good vocabulary and most importantly can generally get his message across.

Having identified clues he was ready, we decided to address toilet training in the summer holidays when he was six. He made progress but struggled on his return to school. As he was anxious, we took the pressure off and left it. One morning, he suddenly refused a pull-up, ran upstairs and used the toilet. I let him have control, offering either a pull-up or boxer shorts. After worrying we would never achieve it, that was it, he was using the toilet!

Harry's preferred drink is still apple juice, but he will tolerate orange juice and blackcurrant. School achieved this by offering it daily.

It's been lovely to look back and reflect on how far he has come.

Alec Elley

January 2013, Age 10

When co-editor of AuKids Debby first wrote about Alec for this piece, communication and independence were her two priorities. She wanted Alec to be dry at night and to vocalise words more clearly. He used PECS cards to make requests, but she felt it would be nice if he could comment on things as well. She wanted him to be able to dress himself and brush his own teeth.



A year on and by the age of 11, Alec was dry during the night. This had simply been achieved through perseverance, with the aid of waterproof sheeting from Brolly Sheets plus some Bed Mats from Huggies Dry Nites. Alec was rewarded with a chocolate button every time he took himself to the toilet before bed (dentists look away), his parents danced around making a fuss if he was successful and reduced the amount he drank after tea.

By the age of 11 Alec had no clear words but was vocalising more. He could hold his own trousers and pull them up, but this took a great deal of time. He learnt to clean his teeth with 'hand over hand' support from mum.

July 2020, Age 16

By Debby Elley, Alec's mum

Even though he remains non-verbal, Alec draws our attention to anything that interests him, vocalizing. He follows instructions and his understanding of language is improving all the time.



Communication has been developed through PECS and an iPad app by Tobii Dynavox called Snap and Core first which is very flexible; we have programmed it with the words he uses most. His teachers have worked hard to help him identify different groups of emotions so that he can express when he isn't feeling calm.

Lockdown has assured us of the time we needed to overcome those final hurdles in the ongoing getting dressed saga. Alec's difficulty is he loses focus very fast and is easily distracted. But after helping Alec for many years and 'fading' our support very gradually, plus some help from occupational therapists at school, we are now able to give him purely verbal prompts, and he will choose what he needs from cupboards and get himself dressed. As he problem solves, you can actually see that he's developing 'muscle memory'. He is almost at the stage where we can leave the room whilst he dresses.

Alec's now completely independent with toileting, so much so that the early struggles we had to get him to this point are a distant memory. Worth the wait!

Every day we look for opportunities for him to do things himself, in line with his motor skills and in tune with his patience levels, so that he continues to develop. For Alec, motor skills have dramatically improved also, paving the way for more cognitive development.

And whereas before he used to resist doing things for himself, now he seems to enjoy it more because he's witnessed the satisfaction he gets through achievement.



Supreme Plasticine

Normally, *The Last Word* is written by co-editor Debby Elley. Back in 2008 when we started up AuKids, Debby's autistic twins Bobby and Alec were four. The twins are now 16 and although Alec can't comment on Debby's writing, Bobby has started to read her early columns, articulating his own perspective looking back. We decided that you might like to read his thoughts, and so for the final year of AuKids, Bobby is taking over this space!

In Issue 4 of AuKids, my mum's column focused on my latest special interest – the Change4Life cartoons. She told you how at the age of 4 I quoted lines from this TV advert repeatedly. But why did I do it? I'll explain...

Television adverts have always been a hobby of mine. And some of Aardman's adverts are no exception. Especially Change4Life. It was one of my obsessions in 2009. Looking at it today, I can see why I liked it. The animation was simple. The plot was easy to understand. And even though it was an advertisement for a campaign which promotes healthy eating and exercise, I still find it entertaining, even today.

.....
“So why do I like TV adverts? Three words: simple, short, exciting.”

The animation is so simple; the colours are so simple - it's fantastic. And I'm sure lots of other autistic people would agree.

Now let me tell you about why I quoted it in primary school. I liked this advert so much, that I couldn't help just playing it, like a YouTube video on repeat in my head, without any awareness to whom was talking to me whatsoever. I just liked the thing so much that I had to remember these adverts and retell them repeatedly. I wouldn't be

surprised if people compared me to a broken record!

And that was not all. I watched lots of other TV adverts over time as well. I especially liked those adverts with mascots. For example, Monkey from PG Tips, the meerkats from Compare The Market and most importantly, Underdog, from the National Accident Helpline in the 2010s. And like Change4Life, I started repeating that in primary school as well.

When I repeated those obsessions, my teachers would get what I meant, because they'd obviously seen those adverts before. I'm cringing writing this, but it is truly worth it to experience the nostalgia I'm feeling right now.

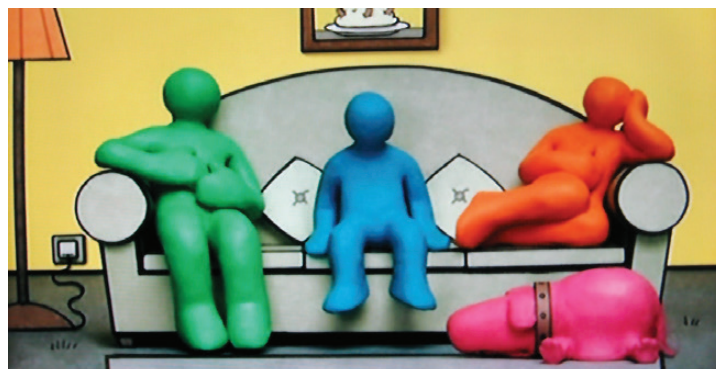
So why do I like TV adverts? Three words: simple, short, exciting.

The TV adverts are simple. They're easy for the autistic mind to process and once they get the hang of it, they can remember it off by heart, like a song or a poem. They know what's coming in the

advert, whether it be a phone number, a website, a price, a shop, etc. They're also short. Whether they range from ten seconds to a minute, my autistic mind is comfortable with the duration of the advert and can remember it in one go.

And finally, they're exciting. There's a lot of action and movements in most TV ads, which stimulates the autistic mind and allows us to copy the actions when we re-enact it.

I also quite like gameshows, specifically ones such as Catch Phrase. I know what you're thinking. "How is this relevant to autism?" Game shows are



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also a triumph of repetition for autistic people. The episodes and contestants on each show are different, but the host (depending on the series) and the idea of the game is the same, whether it be physical or mental, or even both. And autistic people like repetition. They know what's going to happen, beginning to end, with a few twists and turns in between, but no drastic changes.

I still like watching TV advertisements now, even if I'm not as obsessed with them as I once was as a younger child, they're still fun to watch. And hey, I go on YouTube and search for these ads, just for nostalgia.

Aardman is one of those companies that has inspired me to go further and to create my own animations in the future, not stop motion though, but CGI.

So, in short, simple is great. Even something as short as a TV advert can inspire us.

You can read Debby's original column in Issue 4 at www.aukids.co.uk under Downloads.



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