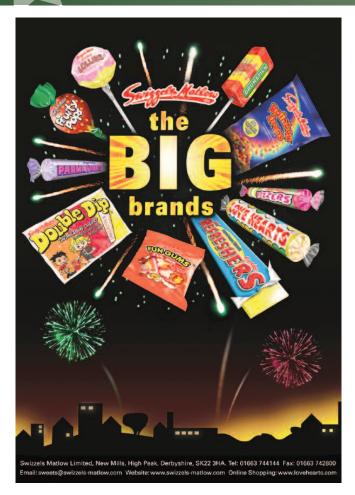




Positive Parenting for Children with Autism Spectrum Conditions



Letter from the Editors





# Welcome to

A long time ago... 2008 actually... in a galaxy far, far away...well, in Cheshire actually...a positive parent, Debby Elley, met a positive professional, Tori Houghton. Debby had five year old twins with autism and Tori was at the time their speech and language therapist.

It wasn't at first a meeting of minds. Namely, because Debby was in that I'mgoing-to-learn-everything-about-this-if-kills-me stage and far too busy focusing on what Tori was saying to think about creating a magazine. Life was a juggle comprising Thomas the Tank Engine DVDs, speech and language therapy sessions and heavy-duty bedtime reading on autism.

For her part, Tori had a full-time career as a speech and language therapist. She was also part of a research team. Added to that she was thinking of starting up her own support agency for autistic kids (which she did, called Time Specialist Support). And then there was the question of putting the consulting room the right way up again after Debby's twins had visited...

Still it had to be said that we hit it off pretty much straight away. After each therapy session, we'd compare notes on great books we'd seen, great places we'd been... "Why isn't there anything that you can read where this is written down?" said Tori, ever the parent champion. We agreed that word of mouth is a risky thing to rely on for knowledge and information, especially

if you're one of those parents who has their hands so full that they're not exactly in the mood for socialising or joining new play groups. Debby had experienced her fair share of those and knew what it was like to feel isolated but prefer staying at home to the experience of enduring strange looks from parents of 'normal' kirls

"We could start our own magazine!" suggested Tori – and it seemed a good idea. Debby had been a journalist and had first hand experience of autism, Tori had bags of knowledge, enthusiasm and a personal touch when it came to understanding families' needs – why not?

Well there were a hundred reasons why not, but we did it anyway. AuKids is the result

AuKids focuses on the practical. Imagine us as a friend who knows quite a bit about autism. That friend who, over a coffee, shares accumulated wisdom built up through many years of experience.

That friend who shares advice; sees a great speaker and has to tell you about them - reads a great book and has to share it with you! We're the friend in the know, that's AuKids. And we never forget that you know your child best.

At first, with generous sponsorship from Standard Life, who printed the magazine for us, we kept Aukids small and local. But within a year our colourful style had taken off (by this time graphic designer Jo Perry of Periscope Studios had joined us). People liked the magazine because we sifted through confusing information and translated it in a down to earth, jargon-free style. Word spread and Aukids became a subscription magazine covering the whole of the UK.

With the help of a small subscription charge, we could now cover our own graphic and print costs. Before long, we had a back catalogue of useful articles, and a growing fan club. Tim Tuff, an adult with autism, joined the crew and helped us distribute to our growing number of subscribers. He was also good at finding more potential ones! So now we are four. As well as writing the magazine, we like to bring some of our articles to life by demonstrating our ideas at conferences. Tim also talks about his own experiences and why he became involved with the magazine.

In 2015, AuKids scooped the title of Specialist Magazine of the Year at the Prolific North Awards. The judges praised the magazine's innovative and humorous style. Our magazine, still so small in size by most standards, had achieved media recognition outside our own autism arena. Cash is always an issue when you're a social enterprise, but this accolade encouraged us to keep going.

The Starter's Special you're holding now is a selection of our best articles compiled especially for people who are at the early stages of an unfamiliar journey. We hope that you like it and most importantly we hope that by reading it you'll realise that you're not alone. There are so many parents out there with exactly the same questions and concerns as you. See us as part of your support network.

Welcome to the AuKids family!



e-mail: editors@aukids.co.uk

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

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

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# A Letter to a Parent





ME WITH THE TWINS

MOSES AND TORI

ALEC SCOFFING SNOW

My twins were brilliant during the ADOS\* test. Okay, so they didn't succeed at the pretend play quite clearly that block of wood was NOT to be confused with a plane - but they were still engaged. I thought the testing team couldn't fail to be impressed with just how lovely they were. So they couldn't

Wrong. Lovely or not, they were still deemed to sit firmly inside the autistic bracket. It was a test, be autistic, right?

So, they've got this autism, I thought, and they're not normal. It probably means that they won't and it felt like they had failed it. do anything that's 'normal' and we'll never have a 'normal' life. Maybe we can write off being a happy,

That was almost ten years ago. I still have autistic twins, and let me tell you that rather than 'normal' family, too. tarnish my happiness they have made me the most optimistic and proud mum I could have ever hoped to be. They've taught me to see life from a different angle and to define success differently - for me

They've taught me that it's wrong to label someone as 'abnormal' because they're different. and for them. And as I've learnt about this fascinating, complex condition, I've learnt how to adapt. These days, I co-edit AuKids to help others do the same, with a passion that I've never had for any other job. you may hear some people talking about autism as though it's a nightmare. Don't let those people

scare you. Our experience (that's Tori's as a professional speech and language therapist, and mine as a parent) is that if you understand your child, find out what motivates them and read their subtle communication signals, then they respond positively. Don't let the label 'autism' scare you into thinking you don't know your child anymore. However little you know about autism right now, knowledge of your child will always be your biggest asset.

So much changes over the years. Things happen that you thought you'd never see. Your journey does not have a definite path and the scenery is ever-changing. So just enjoy what you can each step of the

way and don't try too hard to predict, just have faith. Keep believing, keep encouraging, keep being positive, and you'll be rewarded with those special steps. Adjust your expectations to the child and don't compare them to someone without autism. No point. you may as well start getting depressed that the orange in your fruit bowl will never be an apple.

Seek out positive people. Learn about ways to help your child but don't stuff your head full of it to the extent that you're not enjoying the here and now, because having a laugh is brilliant for bonding and

Beware: there's a lot of cowboys out there who advertise 'cures' in well-respected places. development. Stick with trusted advice from the likes of The National Autistic Society and keep up to date with www.researchautism.net who at least endeavour to filter out the more suspect claims.

Finally, there's us, your 'mate' in the know - AuKids magazine! Tori and I launched this magazine because we felt there was a lack of help available to parents in your situation. We take tricky concepts and we turn them into easy-to-read articles. Our ethos is to make learning about autism fun, so that any parent can be confident in their new-found skills.

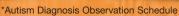
I left our twins' diagnosis with nothing but a head full of worries. Ten years later, I realise that half of those worries were pointless. I didn't know any better as I didn't know

We are a team who know about autism because we live with it. We'll always give you about autism. sound, impartial advice in a witty and colourful way and we hope that you'll always finish the magazine with a big smile on your face, feeling better, encouraged and motivated.

Good luck and enjoy the magazine!

Debby Elley Mum to Bobby and Alec, Twins with autism.





ER...YOU WHAT?

Your out out and keep

# RON BUSINESS

It's a minefield this autism business, not least because the world seems determined to abbreviate everything to the point where it's unintelligible. Fear not, W.H.T.H... (We're Here to Help...) with your very own AuKids guide to common terms and abbreviations.

### 1) Diagnosis terms



### A.D.O.S. – Autism Diagnostic Observation Schedule

If your child has been officially diagnosed, chances are that they would

have had the ADOS test. This isn't scary. Expect a couple of professionals (usually a paediatrician and a speech therapist) playing with your child and having fun. You might find that an educational psychologist looks on from another room. Parents can be present.

The team isn't looking for the absence of 'normal' behaviour, rather the prevalence of autistic behaviour in terms of social interaction, language and imagination. There are some play scenarios during the test that involve the child having to imagine that an object represents something else. Young autistic kids might well struggle here.

The total is totted up and your child will have scored somewhere on the spectrum if they have an...

### A.S.D. - Autism Spectrum Disorder

This is the usual term for being on the spectrum. You also might hear it referred to as **ASC**, **Autism Spectrum Condition**, which is AuKids' preferred term.



#### P.D.A. - Pathological Demand Avoidance



A relative newcomer to be recognised as part of the spectrum, this condition describes a child's extreme reaction when facing normal requests. The National Autistic Society holds its first PDA conference this month.

### P.D.D. - Pervasive Developmental Disorder

This condition is an umbrella term under which autism is one condition. Sometimes in the early days it may be suggested that your child has PDD because there's not yet enough evidence to suggest autism. This term isn't widely used in the UK. Not to be confused with P Diddy, who is an American rapper.



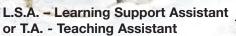


### S.P.D. - Sensory Processing Disorder

It would be unusual for anyone with autism not to have some degree of SPD. You can also have an SPD without autism. Difficulties with sensory processing (the brain experiencing sensory information in an unusual way) is usually a

significant part of autism. The best book we've found on this is Olga Bogdashina's Sensory Perceptual Issues in Autism and Asperger Syndrome, published by Jessica Kingsley. Don't be put off by the title, it isn't a heavy read. See Issue 2 in our online archive for a review.

### 2) People



If extra support in school is deemed necessary, your child will be assigned an LSA or TA who will help your child access the curriculum on an individual basis.



#### O.T. - Occupational Therapist

Most autistic children have some form of Sensory Processing Disorder (S.P.D.), even if it's mild. If the nervous system is all over the place trying to regulate

confusing input, then your child's focus may not be great and it could also have a knock-on effect on behaviour.

Occupational therapists devise programmes of activities designed to regulate the body's nervous system and help with some of those sensory difficulties. The activities will vary depending on whether your child is often in a state of high or low arousal, but they can be practised at home and could make a big difference.

Ask your health visitor or SENCO for a referral to occupational therapy.

#### **Portage**

Portage literally means 'to carry' and these play therapists can be worth their weight in gold if you're in an area where you qualify for a Portage visitor. Your play therapist will show you great games to help your child build on skills that they may not have learnt naturally. Filling in those gaps early will aid development. Look up the National Portage Association at www.portage.org.uk to find out more.



### S.A.L.T. or S.L.T. – Speech and Language Therapist

Unfortunately there is no acronym PEPPER although we can make one up if you like. Hopefully after the ADOS you will be

assigned a speech and language therapist to help you develop your child's communication skills. It's not a question of handing a child over to be 'fixed' by a speech and language therapist, though. This is a slow, steady campaign and will involve you being trained by a speech therapist to look for daily opportunities to develop communication.

### S.E.N.C.O. – Special Educational Needs Co-ordinator

This is a teacher who is qualified to oversee the progress of all SEN children in the school.





### E.P. – Educational Psychologist (sometimes Ed Psych.)

The EP may come on board to help with diagnosis, can assess learning ability and is usually a major part of the statementing process.

### 3) Education terms

### C.A.F. – Common Assessment Framework



For a full explanation and further notes, go to the Department for Education online at www.protectingchildren.org.uk/cp-system/child-in-need/caf

CAF forms are designed to be a one-stop shop, used for access to services and professionals. Those involved in your child's case can refer to CAF so that they can see at a glance the needs of your child and who is on board. The **pre-CAF** form can be used by practitioners to help them decide whether a full needs assessment is necessary.

After getting your consent, the CAF form will identify areas such as services already working with you, current home situation, behavioural and emotional development, self-care skills etc. This forms a basis for joined up working. Some local areas have an electronic version of the CAF form and a national electronic-enabled version of the CAF is being developed. This is called eCAF.

**DeCAF** – That's just how we like our coffee.

#### E.H.C.P. - Education, Health and Care Plan

The old 'Statementing' system has now been replaced with EHC plans. They provide more joined up working between health, social care and education services but give parents the same rights as Statements did. They're an improvement on the old system..

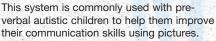




#### I.E.P. - Individual Education Plan

This is a plan agreed between school and home to help a child with a statement to achieve their own personal targets.

## P.E.C.S. – Picture Exchange Communication System





If you want to know a bit more about it, look up Issue 5 in our online archive



### SEN - Special Educational Needs

Any child with an autism or Asperger's diagnosis will be considered to have an SEN even if really clever. This just means that you child's school is obliged to meet their different requirements and may have to adapt accordingly.

### 4) Other support

### C.A.M.H.S. – Children and Adolescent Mental Health Services

Your GP can make a referral to CAMHS. This is an area where the Department of Health and Department for Children, Schools and Families (DCSF) work on joint initiatives. As part of the You Need to Know initiative, the NAS has brought out several information leaflets to answer questions on CAMHS – look up www.autism.org.uk and search CAMHS.

The ADOS has confirmed it's ASD; the SENCO will arrange an LSA and IEP, we'll get an SLT and OT and you should get DLA and advice from the NAS.





### D.L.A. - Disability Living Allowance.

Once your child has been diagnosed, you may be eligible for this. Your local Welfare Rights officer may help you to fill in the form – ask your health visitor to put you in touch. Even if

you're used to forms, it's a real toughie, as it asks you to evaluate the extra time it takes on certain every day tasks because of your child's disability. That can be really difficult to quantify for a kid with autism, so if you can get someone to help you to fill this in we'd advise it – co-editor Debby did. If you're a subscriber and you need more info on other benefits, look up Issue 7 on our online archive at www.aukids.co.uk, which has a benefits guide.

### N.A.S. - The National Autistic Society

Pretty much your one stop shop for information and advice relating to autism. Look them up at www.autism.org.uk If you have joined AuKids online, you will have had the opportunity to request information from the NAS when you joined.



# I.A.S.S. network - Information, Advice and Support Services network

IAS Services have a duty to provide information, advice and support to disabled children and young people, and those with SEN, and their parents. There should be an IAS Service in every local authority. Go to www.iassnetwork.org.uk to find your local one. Sometimes they are referred to as P.P.S - Parent Partnership Services or the Parent Partnership Network.



### Last but by no means least, a few AuKids acronyms



### P.E.P.A. – Practising Essentially Poncy Abbreviations

As promised our own acronym to go with S.A.L.T. This refers to most of the organisations we know.



K.E.T.C.H.U.P. – Kindly Explain
The Codswallop to Help Us Parents

# Pass of the leaves

# Our parents share their words of wisdom

A diagnosis brings with it so many emotions. Wading through those early days isn't easy, in fact this is probably the steepest learning curve you've ever experienced.

You may not always have the fortune to meet someone who's been through it all and can pass on a gem or two, but we have! AuKids approached a group of parents whose children were diagnosed with an Autism Spectrum Condition over two years ago. We asked them what they'd do differently if they could do it again. Here's what they told us...

"What I wish I'd done? Got help and support sooner. Listened to more people who had been there and not tried to do everything myself you just get knackered. Laughed when Mark did something funny, rather than worry he only did it because he is autistic. Be proud of what he could do, not upset about what he could not. Mark is 80 per cent a little boy, 20 per cent autistic - so I should have spent 80 per cent of my time enjoying the 80 per cent, not worrying about the 20 per cent!" Mark's dad, Rick.

"I wish I had taken more risks earlier. Doing something outside your child's comfort zone or taking on a new experience doesn't always result in tears and tantrums. Sometimes there are new things that your child will embrace and enjoy. Sometimes it's worth the preparation and can be a rewarding and positive experience. Travelling aboard, going to a restaurant or joining a climbing club have opened up Oscar's world. However, it does mean sometimes taking the bad experiences on the chin!" Oscar's mum, Lesley.

"I wish I had not concentrated on other people's negativity to my son which could be so hurtful and demoralising. Over the years I have armed myself with a thick skin, a wicked sense of humour and a wealth of razor sharp responses. Remember it's their ignorance - not yours." Oscar's mum, Lesley.

"Spend time talking to other parents and attending groups, even if they are not specific to autism. Other parents have been the biggest strength to us. They have been able to share experiences been a wealth of information and support." Shiloh's

"Don't assume 'professionals' have all the information and solutions. I have the greatest respect for those who have worked with my son and been able to say 'No, I didn't know that, thanks for that info, I'll look into it.' Do your research. Be prepared to be unpopular - you are your child's advocate." Shiloh's mum, Lorna.

with us that 'professionals' just could not touch. Also, they have mum, Lorna.

"My advice is

that you cannot "I wish I'd not deal with everything, spent too much so make sure you energy comparing pick your battles Joe with his peers. No wisely." Mark's matter what your child is dad, Rick. like, no-one likes a competitive mum!" Helen, Joe's mum.

Mark and Rick

"I had a different experience than most people here because we were still living in South Africa when Helen was diagnosed. There was no support groups or anyone else to talk to, so it was an extremely distressing and depressing time for me. For someone living in the UK, my advice would be to talk to as many people as possible. I went to the support group meetings of the National Autistic Society until I had to start working. They were wonderful, and it was so good to talk to other parents of

children with autism." Helen's mum, Bobby. "I wish I had not felt guilty about my son's sibling. My eldest son was five years old when Oscar was diagnosed. He experienced the emotional ups and downs alongside me. I felt guilty he didn't always get 'mummy time' because mummy was dealing with a trauma or two. He is now 14 years old. He is a beautiful, well-rounded,

what they seem. He is incredibly proud of his brother's achievements. Given his age, he is deeply embarrassed by his mother - but not of his younger brother." Oscar's mum, Lesley.

Lesley and Josh

"I also wish I'd been more proactive in getting all the benefits I was entitled to as soon as I could (e.g. Disability Living Allowance) so that you have that bit of extra money if you need to hire babysitters or whatever." Helen's

"I wish I'd trusted my instincts: Ed ended up in hospital for several days having been dismissed by three different doctors because he didn't behave like a typically ill child. Generally, you really do know best!" Ed's mum, Katie.

"I wish that I had written a daily diary on

Joshua from being one.

Then I could look back more

at how much he has come on

and show him when he is older

just what we did for him. I also

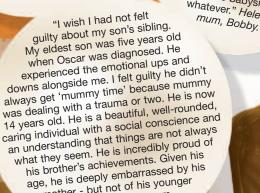
wish I hadn't spent so long

trying to blame myself and

just accepted him for who

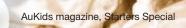
he is." Joshua's mum,

Lesley.









"We learnt to concentrate on helping him to listen, not just to talk." Ed's mum, Katie.

"I wish I'd focused more on what he could do, not on what he couldn't. Being able to see the positives in your child is so much more encouraging." Connor's mum, Elaine.

"I'd have spent less time being a therapist and feeling guilty about how much I was doing to 'help' my child and having fun. You only learn later that as good for autistic kids as sitting them I'm sure kids sense the pressure on pressure off and they tend to be mum, Debby,

"As well as guilt,
pride and anger influencing
parents' behaviour (and
therefore decision-making) I think
ignorance about the condition of
autism also plays a large part.
Speaking personally, if I had my time
again, the first thing I would do is
educate myself with all the information
about autism, child development and
brain development that is coming
out of cutting edge research.
Philip's mum, Zoe.

"I wish I'd asked
for help earlier. I thought
'I can handle this, I'm their
mum,' and it was only after I'd
that I admitted I needed some
mean that you're a poor parent.
came, all my energy returned
with it." Bobby and Alec's

for help finally
with it." Bobby and Alec's

"It's hard to
watch your child work
so hard to learn the
simple things we take for
granted like playing or
talking, but in hindsight the
sense of achievement when
they succeed makes it all
worthwhile." Ed's
mum, Katie

"I know all children are
different. Some will be able to
achieve a lot as they get older and
others may not. When Daniel was a toddler
I didn't think we would ever be able to get him
to speak. The future seemed very bleak, but he is
now 12 and in a mainstream high school that just
happens to have experience with ASC kids. He's a
fantastic boy and is doing very well and making such
fantastic boy and is doing very well and making such
wonderful progress the older he gets. He's very happy at
his new school and we are all very proud of him.

Bobby, Debby and Alec

I heard so much negativity about Daniel's future when he was younger, I just wanted to inject a bit of positivity to anyone reading and feeling a bit down about their child's future. It can be very isolating and difficult when they are young. I know how that feels but things do get better. I wouldn't change a thing about Daniel now and with the help of everyone around him he is growing into a lovely young man."

Daniel's mum, Jackie.





**Airport Parking Shop** 

Compare & Book

### **Airport Parking Shop and autism**

Our *modus operandi* is finding you the best airport parking, but our passion is making all aspects of your journey easier.

We looked at how Airports assist those with autism and you can check out our results and tips here:

https://www.airport-parking-shop.co.uk/blog/uk-airports-need-step-assistance-autism/



## A Spectrum of Light

**Inspirational Interviews with Families Affected by Autism** 

By Francesca Bierens

Published by Jessica Kingsley Publishers ISBN 9781849050135 £12.99

After we'd approached our own group of parents for this feature, AuKids came across A Spectrum of Light. Check it out for even more heart-warming stories and pearls of wisdom from parents.

It's written by a Speech and Language therapist, Francesca Bierens, who has interviewed ten families of children with autism spectrum conditions over 14 years. The book contains extracts from these interviews in the parents' words - real and unabridged. These are wonderful realistic views of journeys, the highs and the lows of life with a child with autism. The message that comes out loud and strong is that even though there may be difficult times, there are many more good times and

many more good times and celebrations. The last chapter contains extracts from follow-up interviews with the original families 14 years later, including interviews with two of the children, now adults

Each page contains a quotable nugget of advice but we've selected some of the best ones to complement our own parents' pearls..... Enjoy!

"It's about making things fit for Joseph not Joseph fit into things and that just goes a lot more smoothly" Joseph's mother.

Taken from A Spectrum of Light.

"It's finding ways
to help her with that
particular obsession. How
can I make that particular
interest work for me so that it
doesn't drive me crazy? I
wish I'd known more of that
when she was younger."
Eleanor's mother.

Taken from A Spectrum of Light.

"They (my parents) accepted me for who I was. It's understanding. It's knowing this person is different and you're respecting them for it. You're not trying to change them. It's not a disease. That's just something you have to work with."

David, who has autism.

Taken from A Spectrum of Light.

f you're a parent reading this, the chances are that your child has been or will be diagnosed with an autism spectrum condition using the ADOS (Autism Diagnosis Observation Schedule) test.

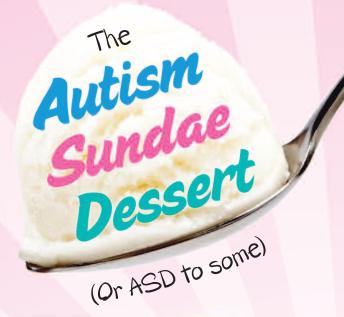
This can leave you with the impression that autism is some sort of continuum.

Actually, the nature of autism isn't like that.

Rather than imagining it as a graph with 'high functioning' on the bottom and 'really severe' WARNING! at the top, we prefer to think of autism as a This feature may series of ingredients. Whilst three core ause a craving for ice-cream. We advise elements define autism, many other traits appear to different degrees or not at all you to get some in the freezer before reading depending on the person's condition,

To illustrate this, we've come up with the perfect image - the ice-cream sundae.

personality and environment.



# The Definition of Autism

Traditionally, in order to be diagnosed on the autism spectrum, a person has to have three key ingredients - here shown with the traditional Neapolitan ice-cream. You may hear this termed the 'triad of impairments' but AuKids has never liked that term very much, as it implies that a person is lacking. We're not sure that Alan Turing or Isaac Newton would have seen themselves as impaired, for instance. The three key ingredients are:

- Difficulties with communication. here represented by **CHOCOLATE**.
- Difficulties with social interaction here represented by VANILLA
- Difficulties with imagination, here represented by **STRAWBERRY**.



# Different Dollops

Why is autism so varied? Not everyone has equal dollops of ice-cream. Some may have less vanilla and more strawberry, some more chocolate but less vanilla. Some may have very little of all three. All combinations are possible. As long as the 'Neapolitan' combination is present, they have autism.

Although the Neapolitan combo remains with a person all their life, those dollops may well change in size over time. With some encouragement, children can develop communication skills and social skills. Imagination can also change and develop over time. The 'look' of their autism won't always be the same as the day they were diagnosed.

# The Flake

People sometimes think that someone with autism comes with behavioural challenges as part and parcel of the condition.

Not so. That's why we've added a Flake here to represent behavioural difficulties. They can be added and taken away, just as with any other child. Lack of an ability to verbalise can cause frustration, but if you ease that frustration by providing other methods of communication, you are less likely to get behavioural problems as a result. So it's not just the 'chocolate' that's responsible.

Isolation as a result of social difficulties can cause problems. Or a child may be perfectly happy playing by themselves, and frustrated at adults' attempts to 'make them' socialise Challenging behaviour doesn't come with the territory and can be affected or change itself over time. The key is to know your child and to deal with any negative knock-on effects of the autism as soon as you can, by understanding the source of their behaviour.



\*Recent changes to the DSM-5 (diagnosis criteria) describe 'vanilla' and 'chocolate' as one element of autism and repetitive behaviour and routines as another. The World Health Organisation's classification criteria (ICD-10) largely used in this country, remains unchanged.

# Chocolate & auce

It's very rare that you get a Neapolitan without anything added.

One common aspect of autism, now recognised as playing a major part in a child's behaviour, is sensory issues, which we will represent by chocolate sauce, as they impact on all of your ice-cream and not just some of it.

A child can have sensory integration issues without having autism. Sensory issues, however, almost always come with autism, so much so that in the recent diagnostic criteria they are given particular emphasis. The combination of sensory issues and the key ingredients of autism can impact on a child's behaviour.

For instance, social difficulties (vanilla) may appear more extreme if sensory issues mean that a person gets overwhelmed by noise and crowds. How do you learn social rules when you're busy defending your nervous system from overload? Very tricky.

This is what makes it so hard to define a person's autism clearly. It might be hard to know whether you're looking at a large dollop of vanilla, or just a medium-sized dollop of vanilla with a lot of chocolate sauce on it!

It's not enough to assume that the core traits of autism are themselves responsible for a child's difficulties. Look for clues as to how a person's environment (sights, sounds, smells, tastes) is affecting their behaviour. Although autism is a lifelong condition, helping a child with sensory difficulties – and any other challenges that make them uncomfortable - can really impact positively on their overall behaviour and wellbeing.





# Stramberry Sance

Our next ice-cream sundae comes with strawberry sauce. This represents other conditions that can occur alongside autism (referred to rather alarmingly by clinicians as comorbidity, another cheery term). We have chosen sauce because again, it 'covers' the autism to the extent that you may find it hard to work out what's caused by the autism and what's not.

If a child has learning difficulties, they may not play alongside their peers. How do you know whether what you're witnessing is problems with social interaction (vanilla) or part of their learning difficulties (strawberry sauce)?

It's sometimes near impossible for even experienced professionals to assess what is causing a child's behaviour. What becomes more important is helping them with a particular difficulty whatever its source (or sauce...excuse the pun), whilst being aware that there are a number of possibilities impacting their learning style and considering them all.

# The Sprinkles

Ice-cream sundaes can have all sorts of extras added which we haven't shown here. The need for routine and special interests are a particularly common aspect of autism.

And what about our favourite bit of all...the sprinkles?

Some autistic kids show great skills on top of

everything. Does your child have a good memory, enjoy numbers, love computers? A 'savant' – someone who is at genius level, would no doubt have a high degree of sprinkles AND a cherry on top. But there are still many kids with autism who aren't defined as geniuses but certainly have some fantastic skills, here represented by a dash of sprinkles.





# No Two Sundaes Are the Same!

The Neapolitan sundae is presented in a glass – your kid's personality. Autism doesn't turn children into clones, of course! An outgoing child won't want to avoid other people but will perhaps need to practise their social skills to make them less vulnerable when approaching new people. A child who is naturally shy may feel inclined to isolate themselves more

and would need a double confidence booster to feel able to approach people because of their social difficulties.

So next time you meet a child with autism, remember our Autism Sundae Dessert.

What you're looking at isn't simply a score.

# Ask the Experts

# Obsessed with Trains

Everywhere we go he looks out for trains and if he sees one or a picture of one in a shop he gets very distressed if we can't go in and look at it. I don't know how to manage this. Are there ways in which I can use his obsession productively without feeling like I'm feeding this and making things worse in the long run?



Luke Beardon

Luke is a Senior Lecturer in Autism at The Autism Centre, Sheffield Hallam University

Contact him at I.beardon@shu.ac.uk

First off, the term 'obsession' is one fraught with (usually negative) connotations - so avoid using it if possible. As noted by someone on one of my courses, 'passionate interest' is far more accurate as a definition.

Secondly, so long as the interest is not inappropriate (e.g. unlawful, or detrimental to others or self) then try to embrace it rather than assume the worst. In reality passionate interests are critical for motivational purposes, and can be a great source of comfort and positivity for the individual.

My take in such situations tends to be to turn the whole thing on its head and proactively encourage the interest - but within certain

stipulated boundaries, rather than the more negative way of trying to stop it - which will only be met with resistance! Try and be as structured as possible about encouraging the interest - for example, "When we go out I will help you look for three trains/pictures and we won't come home until we have found them". Or, "If you manage to do the shopping without being distracted there will be a new train picture for you at home when we get back."

Obviously you need to be careful what you promise and this takes a degree of imagination! This approach often gains trust straight away and can reduce the need for the individual to have to engage at every possible moment - because they know there is something to look forward to.

Think to yourself - is it easier to say 'no' to that chocolate/bun/pint/cake if you know that you will get it just around the corner if you wait a bit longer? Similarly, people with autism find it much easier if they know when/how they will be able to engage in their passionate interest, and this should reduce the need to engage in it at every given opportunity.



Dr Paul Holland PhD C.Psychol. AFBPsS

Consultant Behaviour Analyst
Chartered Psychologist
Chartered Scientist
Columnist for SEN magazine.

Obsessional interests are considerable diagnostic criteria of ASC. As long as the obsession with trains that your son experiences does not impact negatively on his ability to learn, communicate and socialize, I would use the obsession to your advantage.

For example you could use the obsession with trains to motivate and reward, develop skills, increase social opportunities and improve self-esteem.

Often I have used obsessions to teach. A multitude of skills and abilities that need to be taught can be taught via trains. Furthermore, these skills and abilities can then be transferred to other areas.

If you think about trains, you may

think of an engine and carriages. But if you really think about what you could be working with, the list grows dramatically: trains have doors, windows, wheels, nuts, bolts, seats, racks, toilets, conductors, drivers, passengers (people), engines, carriages, carpet, metal, glass, plastic, etc. Trains are all different colours, shapes, sizes, lengths, heights etc. Trains can be electric, steam-powered, diesel powered etc. The list goes on!

All of these can be broken down even further: different types of windows, different people, all of the colours of the rainbow, all shapes, sizes etc. In addition to the 'things' that we can use to teach, the areas of teaching are limited only by our imagination. All skills can be taught using trains, for example, receptive discrimination (the ability to identify objects and/or perform actions when given a label or instruction e.g. "Where is the shoe?" or "Clap your hands") expressive labelling, imitation, matching, counting, colouring, requesting, singing, storytelling, playing, etc.

There are obviously many other interventions that you could use to help deal with the obsession but if you can use something that your son truly likes and enjoys to teach and learn, then learning will become an enjoyable experience for you both!









"When I'm feeling poetic I usually compare them this way: An obsession is like an intoxicating infatuation that flames up and makes me giddy, but that sooner or later will fade away quietly and die. A special interest is like true love, it warms me and is always there, I will never tire of it and I'll always feel the same way about it and return to it."

Skilpadde, an adult with Asperger Syndrome as quoted on www.wrongplanet.net



Louise Page M.A.I.P.C., Q.M.A.C.A. (Australia)

Professional Counsellor Author and autism therapist Mother of three young adults on the spectrum

Some obsessive behaviours in children, particularly children who are described as being on the autism spectrum, can be attributed to passionate interests.

To help counteract any distress for your son when it is time to 'move on' and pass the shop window or even a railway crossing, we can become creative in how to kindly divert their intense attention by having, for example, 'portable' methods and/or activities which can relate to what they have focused on, but allow the parent to continue past the 'attraction' point.

Some creative ideas could be obtaining a pasting book in

which a collection of pictures of his favourite trains (styles, colours, 'characters') can be pasted. While travelling with this book, he can compare the trains he sees around him with the examples in his book. He can then be momentarily distracted from focusing on the train picture in the shop window, hopefully to continue on his way with you as he relates what he has seen to the pictures in his scrapbook.

Perhaps if he finds it difficult to move on, you may ask the shop owner, for example, for permission to photograph the train so that your son may add it to his scrapbook collection. On the way home, he can continue to enjoy the captured image and hopefully not be upset by being withdrawn from an intense point of interest. This can then be printed out at home and added to his scrapbook.

By providing a small variety of similar interest items relating to a passion, children can be helped to diversify.

With your son's passion for trains, you may be witnessing a preview of future skills, such as an interest in logical (e.g. mathematical) systems, observations in detail, patterns, structure and design.



**DELTA'S A-Z:** Delta is fascinated by maps. He says "1,000 millions and 20,000 more - this is what maps mean to me".



Katie Moizer

Katie is a Chartered Clinical Psychologist who provides specialist services to children with autism and their families both for the NHS and independently.

For more information call 0788 605 5043.

Your son's obsession is likely to provide him with relaxation, sensory stimulation or a sense of order or purpose to what can often be a confusing life.

A little indulgence in something we enjoy is essential for everyone, provided the obsession is not 'risky' and it doesn't completely take over your life. Eliminating obsessions can be distressing and sometimes unnecessary, so I think your inclination to use your son's obsession with trains *productively* is positive.

You could incorporate time to look at trains at the end of each shopping trip. This should be communicated to your child both before and during the shopping trip in a way that he understands (i.e. using visual cues like symbols or photographs).

I advise imposing a time limit on the activity (by using an alarm on your mobile phone for example) to let your son know when the activity has finished. It is important that you carry out the promised activity while also making sure that you stick to the limits imposed. The key is to limit the time of the obsession in a way that allows both of you to complete important and rewarding activities, in your case shopping and in your son's, examining trains!

# 8

### Do you have a question for Ask the Panel? E-mail us at editors@aukids.co.uk

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

### Seamless Socks & Undies for Sensitive Kids!

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Get them dressed without the drama!!

# Sensary Smart Stare



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THE TEN COMMANDMENTS

OF BRINGING UP A CHILD WITH AUTISM

Ten years' worth of blunders and blessings have led me to a place from which I can look back and view the positive turning points of my life with twins on opposite ends of the autism spectrum. Here I've condensed them into ten messages which with any luck will speed up the learning curve for someone who has yet to climb the same mountain! This is also available as a talk – see end for details.

By Debby Elley



### 1 THOU SHALT KEEP POSITIVE

Keep positive! But what does it mean and how do you do it? The practical advantage of keeping positive is that you become much more efficient at problem solving. You quickly move from recognising a problem to seeking practical solutions that will nip them in the bud. Use your worries to propel you towards practical action. If you hit a brick wall trying to find a solution, back up and try a different route. Someone has been here before you, and thought of an answer. So network to find a solution.

When the twins were young I avoided negative people like the plague. You really don't need other people's often unrealistic anxieties washing over you like toxic waste. It saps your energy. I learnt to see my energy as a positive powerful force, and I guarded it

There really is no mystery to being positive. Happiness comes when something exceeds your expectations. Unhappiness comes when something fails to meet your expectations. If your expectations are constantly very high and your child fails to meet them, you will be unhappy. More to the point, so will they, since even pre-verbal children with autism are very sensitive to a tyting.

I learnt to look at the twins' development through a magnifying glass, seeking out small but significant changes (with the help of professionals like Tori) and focusing on what they could do rather than what they couldn't. Looking for small changes rather than expecting big steps lead to my expectations being met and exceeded more often.

Why are some people so happy in life? It isn't because they are more lucky than you or I, or richer. It's purely down to perspective. That puts you in a powerful position. Choose to see autism as a different way of being rather than a disability – with advantages, not just 'impairments'. Choose to recognise tiny steps forward.



# 2 THOU SHALT NOT BE TOO PROUD

I was plain stupid until the kids were four years old. 'I'm their mum, I can cope, I'm superwoman'. Of course you can cope. The question is – at what cost? This is a marathon, not a sprint folks. The biggest misconception that I suffered was that help was only available to those poor souls about to crumble and that I had no right to deprive them of it by taking it up myself. Help is designed to reach people BEFORE they get to a point where they crumble.

Don't grasp your child tightly to your bosom thinking: 'No one else will understand them like I can!' You'd be surprised. You just need to choose people who understand autism and have the willingness to get to know an individual well. It does them good as well as you.



### 3 THOU SHALT KEEP CALM

Those of you who've been with us for a while will remember that we thought being calm was so important that we dedicated an entire issue to it.

The more calm you are, the more calm your kids become. The more you practise being calm, the better you get at it. For me this means being acutely aware of the volume of my voice no matter what the provocation and however I am feeling inside. I do shout, but it happens when the kids are genuinely being naughty and not just when I'm frustrated and need to vent.

Learning patience and tolerance has improved every aspect of my life. Helping your kids to recognise what keeps them calm is very important, too.



# THOU SHALT SEE THE WORLD FROM THEIR VIEWPOINT

When our family went to see some air raid shelters, Bobby filmed the entire thing on his camera. Looking at the film, it struck me that his experience of the visit was totally different to ours on account of the fact that he is half my size. Added to that, his autism would have made the experience different in two major ways.

Firstly, whereas we have an organised folder system in our brains that allows us to categorise every new thing we come across, for him this doesn't work quite so efficiently. This means that he focuses on detail more, without looking at how that fits into the bigger picture. This observation can sometimes work to an autistic person's advantage and lead to great creativity, but it can also lead to overload.

Bobby's brain is more likely to make links with something recent that he's really into – a whole load of seeming drivel will follow whilst he categorises the unfamiliar according to the world of Sonic, Mario and Raving Furbies.

The second thing that will drive Bobby to behave differently is how his senses process the new surroundings. Sensitivity to sound meant that anxiety over the bombing noises during the wartime showreel stopped him from learning altogether.

If you can't see the world from their viewpoint, it becomes hard to help your child. Fortunately we are living at a time where much is written about sensory integration, some of it mentioned in this issue – and autism is becoming more understood.



### 5 THOU SHALT ENJOY THE PRESENT - IT'S A GIFT

One thing used to marr my early years with the boys, particularly with Alec, was that I felt the need to be his therapist. Any time that I didn't spend helping him to be productive, I felt guilty about. I spent a lot of time trying to help him draw when he just wasn't interested or motivated.

It was only a lot later when I realised that the best therapy of all is having a laugh with your child and mucking around with them. This builds a bond and makes them receptive and confident. And I've now become more adept at building therapy into fun time without making it into a big deal that is a chore for me and for Alec.



# 6 THOU SHALT AVOID COMPARISONS

Neurotypical children are apples, and I have two pears. If you are comparing your pear to apples all the time, it will make you unhappy. I learnt to only compare Bobby and Alec with themselves. Each one of us is on our own journey in life and the only measure of progress should be against yourself.



# 7 THOU SHALT TRUST INSTINCT

Is instinct just a hunch? No, it's actually reasoned judgement, it's just working at a speed too fast for us to comprehend, taking into account many more variables than we could possibly process at a conscious level.

When we're given a diagnosis it can make us question our own natural instincts as parents. But I've learnt that instinct is more powerful and accurate than all the medical knowledge in the universe.



# 8 THOU SHALT ACT EARLY

Finding the energy in the early years to iron out small behavioural difficulties was tough, but boy was it worth it. It started with cartoons after an incident to help Bobby understand how he was thinking and feeling. I learnt to focus on that, rather than telling him off for bad behaviour. Usually he knew only too well that he'd been out of control and liked it even less than we did.

It meant sitting down in the calm after the storm and analysing together what could have gone better next time. It meant listening to his thoughts, recognising and respecting them - and calming myself when I felt like kicking the front door down! It meant helping him to understand the physical and mental signs of frustration and what he could do about them.

I didn't always do it perfectly, in fact I didn't always do it full stop, but I did it enough of the time that it made a difference.



### 9 THOU SHALT NEVER SAY NEVER

We sometimes think that in order to protect ourselves from disappointment, we need to believe that the worst will happen. The problem with this is that it can become a self-fulfilling prophecy. If you don't truly believe that your child with do something, you communicate that in all your efforts, and hey presto you end up getting what you expected.

Plug away and have faith, even if it takes months or years. There is no deadline to development. As famous speaker Ros Blackburn's mother told her:

'There is no such thing as cannot. There is can, but not yet'.

It's one of my favourite quotes.



# 10 CHAMPION THY OFFSPRING

Imagine your best buddy. Now imagine that before meeting them, someone had told you that they could be really difficult to deal with. Imagine how that would taint your perception of them, even if you witnessed no evidence of it yourself. You'd even end up looking for it.

Sometimes we worry whether others will be able to cope with our kids, so we shovel all the negative information their way the minute they meet junior.

Use some psychology when dealing with people who are about to look after your child. Introduce your child with a massive grin on your face and tell them how they're going to love them! Are they a great giggle? What gets the biggest laugh out of them? People who champion your child need to see what you see in them. Then they can take that baton forward and communicate the same message to those around them.

Sure, tell them the challenges, but don't let them be the first thing that you mention.



### EXTRA INFORMATION

If you want to learn more about staying calm, look up Issue 14 – available for subscribers to download online via our magazine archive at www.aukids.co.uk



# Therapies



# Which Way Now?

In the months after diagnosis, it's common to embark on the search for a Holy Grail - the one therapy programme that will provide the 'answer' to your child's autism. It feels like there is so much at stake. There are so many claims, so much hype ...it's not only confusing, it can be quite frightening, too.

Most programmes focus on one or two common therapeutic techniques which we detail below. Our rough guide is by no means comprehensive, but it's a start. At first, we'd encourage you to adopt a pick 'n' mix approach.

It's the technique used and not the therapy programme that delivers it that counts.

The techniques that are best for you will depend on your child's condition, the nature of their personality and different situations. Because of this, it's always difficult to prove scientifically that a particular method is universally effective. When all is said and done, it can sometimes be down to trial and error, and finding a range of techniques that work with your child is something that develops over time and improves with experience.

# Decisions, Decisions...

Assess the risk of a therapy first. If there's no downside, then there's little harm in giving it a go, although make sure that you give a technique time to succeed before you write it off. Be cautious to jump quickly to drug or diet interventions without good guidance first from your paediatrician.

Make sure that any therapy you use does not come at the expense of your family's emotional well-being. Quality time with happy children is the best therapy

of all.

(**©** Always adhere to the advice of your paediatrician.

Don't be guided by people who 'swear' by a therapy's success. No two children on the spectrum are the same. Anecdotal evidence of one child's success should not be a replacement for sound scientific research.

Decisions can be changed. Don't put pressure on yourself to get it right first time. Don't feel a failure if a technique or intervention doesn't seem to be working it just may not suit your child.

Watch your child. Are they happy when you use the therapy? Are they responsive and is there progress? If they're not happy after they've got used to it, then whatever the hype, go with your gut instinct.

-

Some therapies may not suit your child now, but may well be worth revisiting in the future, so don't be disheartened.

As a general rule of thumb, we'd always advise checking out the credentials of anyone who offers a therapy. Make sure that a therapist is trained by an approved body in their field.

Be very cautious about handing over a lot of cash for an unproven remedy that doesn't offer you a free trial and carefully consider the risks and look at research before you try a new therapy.

It may be an idea to see whether your child responds to a certain technique well before committing to a programme that uses it exclusively.

### Scientific FACT or Science FICTION?



**Professor Jonathan Green** is Professor of Child & Adolescent Psychiatry in the University of Manchester. He is also **Honorary Consultant Child** & Adolescent Psychiatrist at Central Manchester and Manchester Children's **Hospitals University NHS** 

Trust and Manchester Biomedical Research Centre. Here, he gives advice on how to evaluate the huge amount of research you'll come across.

New treatments for autism are constantly emerging - often involving great claims of success and families' commitment of large amounts of time and

How to decide then what may be useful before choosing? The Internet is full of conflicting advice and individual testimonials can be misleading. In the end, scientific research into the effectiveness of treatments is the best guide - and this is actually generally no more than the careful application of logic and common sense. Here are some of the questions that researchers bear in mind.

Was this research done with a reasonable number of children and families? This is because you can't generalize the results on the basis of just one or two cases - individual testimonials can be inspiring but may be misleading. It is difficult to conclude much from reports of under about 30 cases.

Do we know what kind of children were treated? If the results are to apply to your child, the study needs to have been done on children like yours - decent research should be clear on the nature of the children studied.

Was there an equivalent group of children studied as a comparison who were not given the treatment? This is crucial, because it is impossible to separate out the specific effects of a treatment from other factors - or general growth and development - unless there is a comparison group in the study. It is really important that the comparison group is as similar to the treatment group as possible - and that can be tricky to do. This is the reason why the 'randomised allocation trial' is so good because by randomly allocating children to get the treatment or not before the study starts we avoid biases in selecting the groups, and we get the best comparison.

What outcomes of the treatment were measured? Are they ones that are meaningful to you or your child?

Were the people rating the outcomes 'blind' to whether the child was getting the treatment? We do this because there is a natural (and very strong) tendency for people's observation of improvements to be influenced by their hope and expectation that there will be an effect. If we want to be sure that the treatment really is effective, and not that we just hope it is, we need to have at least some of the observations of outcome done 'blind' in this way.

Has the evidence been published in a scientific journal - or is it endorsed by trustworthy sources such as the National Autistic Society? This is a good shortcut because evidence is not generally published now unless it meets the points listed above.

Do the people making claims of effectiveness have a 'conflict of interest'? In other words, might they stand to benefit in some way (e.g. financially) from the treatment being taken up? If they do, this should make you look particularly carefully

at what is claimed.

But scientific research is too slow in getting answers - my child needs help now.....! That is so true and I completely sympathise - all I can say is that the pace of research into treatments really is picking up faster now. We will get the answers in the end if we can keep doing this work - and in the end that depends on funding from charities and Government. In the meantime. it may be best to do what seems appropriate, simple and obvious - to get the basics right for your child first before spending time and money on unproven treatments.

### A (Very) Rough Guide To Therapies

These are the common techniques used in special schools around the UK. The list isn't comprehensive. Most conventional education programmes do use approaches from one of the following four categories, though.



Derived from early developmental theory and psychologists such as Piaget, these approaches focus on encouraging typical development by helping the child to fill in the social gaps that they've lost. The therapy is usually led by the child. The child doesn't experience it as 'therapy', but as play.

The adult/therapist follows the child's focus, showing interest in the child's choice of activity or toy. Any behaviours, sounds and actions produced by the child are copied by the adult, showing them that these have meaning.

Key actions and sounds are copied by the adult many times and the reinforcement of them helps to shape intentional communication.

Adult demands such as giving directions and asking

questions are kept to a minimum. Play is based on the child's agenda and so the child is motivated to focus on the communication.

**Especially good for:** Developing meaningful communication and appropriate use of language.

There are a number of child-led programmes which are based on this developmental approach. For more information on these specific programmes go to:

Intensive Interaction: www.intensiveinteraction.co.uk Son-Rise/Options: www.autismtreatmentcenter.org DIR/Floortime (In the US): www.floortime.org



This type of approach comes from early learning theory and behavioural psychologists such as Skinner. Therapy is mainly 1-1 instruction and activities are adult led, breaking down skills into small, achievable steps. Therapy is structured and uses motivators to reward the child after they give

appropriate responses. Generally known as Behavioural Modification, the programmes that use this approach with



children with autism are more commonly called Applied Behavioural Analysis (ABA) or Lovaas Therapy.

This therapy uses what's known as an **ABC** approach i.e. instruction from adult (Antecedent), response from the child (Behaviour) then reward given (Consequence).

One of the main techniques used in behavioural modification therapy is 'backwards' and 'forwards' chaining. This is when you divide a task such as getting dressed into a number of bitesized chunks, then do all but the last or first step for the child, slowly withdrawing support from each bitesized chunk, until the child is performing a task for themselves.

**Especially good for:** Learning self help skills and managing behaviour.



Visual approaches work on the theory that children with autism learn easier with visual support. Many children with autism have language processing difficulties and information presented visually in the form of pictures, photographs, objects or symbols are permanent and provide more obvious clues to instructions.

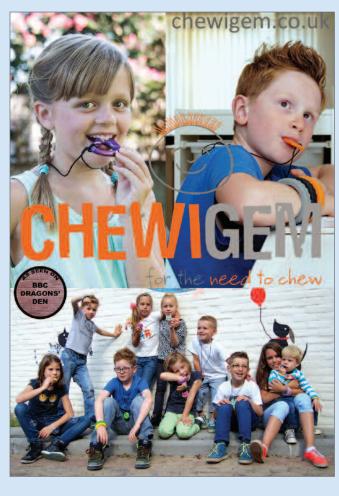
The following programmes and strategies can make use of a child's visual strengths:

- TEACCH Treatment and Education of Autistic and Communication related handicapped Children was developed in North Carolina by Dr. Eric Schopler. This approach focuses on using visual support to help organise the physical environment. For more details go to www.teacch.com
- Social Stories developed by Carol Gray, A Social Story™ describes a situation, skill, or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format.

  www.thegraycenter.org
- Comic Strip Conversations also developed by Carol Gray. This is a conversation between two or more people which uses simple drawings. These drawings explain on-going communication, providing extra support to those who may struggle to understand the quick exchange of information which occurs in a conversation.

**Especially good for:** Visual support helps to generalise skills learnt across contexts and promote independence.

• The Picture Exchange Communication System (PECS) is another visually based therapeutic approach commonly used with children with autism with limited or no language. PECS teaches students to exchange a picture of a desired item with a communication partner, who immediately responds by handing over the desired object and saying the word. For example, if they want a biscuit, they will give a picture of "biscuit" to an adult who directly hands them a biscuit and says "biscuit". The intervention then goes on to teach discrimination of symbols and how to construct simple sentences. For more information go to



www.pecs-unitedkingdom.com

Throughout special schools in the UK, PECS is commonly used alongside Makaton, a simple form of sign language which parents can easily learn and teach to their children. (www.makaton.org)

The advantage of PECS is that it gives children the skills to form intentional communication. This means that when verbal ability does develop, the skills are already in place to make the most of it.

**Especially good for:** Developing basic communication, i.e. requesting needs and wants.



Sensory Integration is a therapy approach offered by occupational therapists specializing in sensory processing difficulties. Many children with autism have difficulty in the way that they process the outside world using their senses, appearing under or over-sensitive to sounds, sights, smells or touch.

Whilst an over or under-sensitive nervous system can't exactly be reset, it can be helped to adapt if the child is provided with different types of sensory experiences in the right way. Therapy usually involves activities that provide tactile [touch], proprioceptive [body position sense] and vestibular [body movement sense] stimulation.

Sensory integration therapy, if it's done correctly, helps the brain to become more organised, and the child to focus better. For more info go to www.sensoryintegration. org.uk

Especially good for: children who have difficulties managing their own sensory systems, usually evident through their behaviour.

### **Summing Up**

We've said that our guide is not comprehensive. There are plenty of techniques out there that are reported to have outstanding results in individual cases, although research on them has until now been inconclusive. They include biomedical and diet interventions and cognitive interventions such as RDI®

(Relationship Development Intervention), each of which deserve a separate article in themselves. The temptation is to try it all. In reality, this is a long road and you've got years to give various techniques a go.

Start simple, don't look for easy and quick answers, and maintain a critical outlook when faced with outlandish promises.

# MELTDOWN5

We're having real trouble managing our son's meltdowns. One minute he's sweetness and light, the next moment he is in an uncontrollable rage and won't listen to reason. His teachers are also struggling. HELP!



**Deborah Plummer** 

Formerly clinical lead speech and language therapist at Leicester, Deborah is now a prolific author and runs workshops and short courses on the uses of imagery, games and story-telling in the promotion of well-being.

www.deborahplummer.co.uk.

Firstly, be reassured! This is not an uncommon situation. Understanding and expressing emotions in acceptable ways is a real challenge for all children. Any child who has reached the stage of 'uncontrollable anger' that you have described will undoubtedly be beyond the point where he is able to respond to requests to listen, be calm, or to explain what the problem is. Because anger is often secondary to another emotion such as sadness, frustration, embarrassment or fear, your son is likely to be feeling confused and overwhelmed. Being out of control is a frightening experience for him.

However, there are a range of strategies that you can use which will help him learn how to regulate these overwhelming feelings. Here are some suggestions for managing extreme and sudden meltdown:

 Remain as calm as possible.
 This gives him a model to follow.

- Make sure that he is physically safe
- Slowly repeat a calming word or phrase such as "You're OK" or "I'm here". It is your tone of voice and your reassurance that is most important.
- When he is beginning to quieten you may be able to add a soothing touch.
   Obviously some children can tolerate this more easily than others
- Try to give him some clear indication that he is succeeding in calming his anger, (a non-verbal sign "I can see you are breathing more slowly").
- When he is calm (this may take some time!) he will be more able to engage with you in problem-solving whatever it was that triggered his 'meltdown'.
- Don't forget, when you talk about this later you might be able to identify another feeling that came before the anger.
- Finally, take time to relax yourself too - it can be exhausting to cope with a child's rages!

There are many other strategies that can help your child to understand that feeling angry is OK but that there are different ways to show this. Whatever you decide works best for both of you, the work you put into helping him regulate these times of rage will be well worth it as you will be helping him to build resilience and increase his ability to understand and regulate his own emotions.



Ask the Experts

Dr Paul Holland PhD C.Psychol. AFBPsS

Consultant Behaviour Analyst
Chartered Psychologist
Chartered Scientist
Columnist for SEN magazine.

Behaviours are not random reactions, they occur for a reason, as a result of a trigger and a consequence. To alter behaviour, we need to know what these are so that they can be addressed.

'Meltdowns' are not uncommon, but the antecedents (triggers) and consequences (what happens after) are typically unique to individual people and contexts.

Firstly, let's talk about the trigger. When behaviours appear suddenly and seemingly at random, it is very frustrating. But removing ourselves and our own reactions to take note of both the environment at the time of the 'meltdown' and also how others react to it is vital.

Due to the complex nature of autism, potential triggers to behaviours are often overlooked. For example, flickering fluorescent bulbs, high-pitched noises, inadvertent changes to routine and other antecedents that WE may perceive as 'typical', could be a trigger.

So be observant of everything that happens and is in place just prior to the behaviour, such as people, time, environmental changes, tiredness or hunger - everything that can be objectively identified. After noting this on a few different occasions, the next step is to link any consistencies and respond accordingly.

Secondly, look at what happens afterwards - the consequences. Behaviours that are maintained by consequences can serve five main types of purpose for a child:

- 1 To receive desired items do we 'give in' after a meltdown?
- Escape do we remove something as a result of the behaviour?
- 3 Avoidance do we decide not to make a typical request of the child?
- 4 Attention do they get a big fuss, even if it's a negative fuss?
- Self Stimulation

For the first four, in order to modify the behaviour, we need to remove reinforcement. A word of warning - when we remove reinforcement from kids, they typically get worse for a while. You would too, if your meltdown had been successful in the past, you'd simply step it up a gear. DO NOT GIVE IN THOUGH...you will only make it worse!

With self stimulation, we often need to look at alternative ways for the required stimulation to be met

Overall, what is often required is both the alteration of potential triggers alongside changing how we react.

"I feel over stimulated and then angry and sad when more stimulation comes in. This hurts, since the cup is already overflowing at this point, so there is not enough room to process everything."

"It's like a sort of earthquake in my mind happens that jumbles my thoughts and makes them race and spill out in a disorganized and unfiltered manner. Following a meltdown, it feels good for a second because my thoughts reorganize (kind of like waking up from a dream state) - then a second later it feels just dreadful when I realize it happened again and I have to deal with the repercussions."

Adult with Asperger's

### WrengPlanet.net

AuKids discussed meltdowns with the adults' Asperger's forum on the Wrongplanet site. Here's the insights they gave us:

'A meltdown should be viewed as a very positive release of pent-up frustrations. Without meltdowns, the frustrations only continue to build up to truly epic proportions.'

'Meltdowns happen at the end of a long string of stresses, so it appears like the last thing that happened in the chain caused it. It's really more like reaching a boiling point and that last event only caused the spillover.'

'Frustrations accumulate because we simply have no way of expressing or dealing with them. They simply pile up over time until it all comes out at once.'

'I need time, peace, quiet, relaxation - and the emotional outburst expressed in the mattdown itself.'

'What helps? Stimming, (repetitive movements - ed.) taking a break, breathing exercises, meditation, physical exercise, attending special interests, education to deal with daily life situations - and a calm and friendly person no matter what.'

'Neurotypicals (people without autism - ed.) need to know that many of us can handle FAR LESS stimulation than you constantly provide for us.'



### **Prevention is Better Than Cure!**

Using a sand timer or a battery-operated timer to 'count down' an activity before it ends is a great way to avoid meltdowns at transition times. You'd be surprised how much a clear, visual warning can help. We love the Big Red Timer from Explore Your Senses at www.exploreyoursenses.co.uk and you can get sand timers from the same source. Or try a Time Timer app.



Luke Beardon

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

I think that there are four main things to take into account here:

- 1 There will always be a good reason for these meltdowns.
- Removing the cause of a meltdown is almost always a preferred option though rarely, if ever, an easy one!
- While meltdowns are difficult to manage and witness, do remember that they do serve a very real purpose, often a release, which can be cathartic and beneficial to the individual.

4 High levels of emotion lead to a decreased ability to process information.

This last point is one I would like to expand on. The fact that he 'won't listen to reason' is very open to interpretation. Quite possibly, if he is in a high state of distress, it is more likely that he can't listen to reason. In the same way that in the highly stressful job interview you only think of the perfect answer after the interview is over, individuals with autism find processing information almost impossible when in high states of arousal.

Thus, it is almost always preferable to have the 'reasoned discussion' when the individual is calm, not when they are in meltdown mode.

Secondly, when having those discussions, try not to put a neurotypical slant on the situation. Ask yourself, whose 'reason' is it that you are referring to? If it is neurotypical reasoning, then it may make little or no sense. Similarly, telling him that there was no need to get angry is nonsense - if there really was no need, then it wouldn't have happened!



# Do you have a question for Ask the Experts? E-mail us at editors@aukids.co.uk

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



# Further Reading

Anger Management Games for Children
By Deborah M Plummer

Published by Jessica Kingsley • ISBN 9781843106289



#### Helping Children to Cope with Change, Stress and Anxiety

- A Photocopiable Activities Book By Deborah M Plummer Published by Jessica Kingsley ISBN 9781843109600

From Anxiety to Meltdown

By Deborah Lipsky Published by Jessica Kingsley ISBN 9781849058438





# Fire Fighting

Jennifer Anzin is an author who has worked with children with special needs for more than 25 years. Her website offers free downloadable books for



parents and teachers to help children deal with anger. Arthur the Angry Engine and Frederick the Fidgety Fire Truck use concrete strategies including counting, deep breathing and yoga. Two more free stories are to be uploaded soon. Look up www.thewhisperersaga.com for more information.

## Parent Tips

"My little boy used to bash his head during a tantrum. It was really difficult to ignore, but we knew that it wasn't severe enough to harm himself, just to cause a reaction. We took away

the reaction, ignored it then rewarded him by loads of attention as soon as he stopped. Believe it or not, it worked. But I know that you can buy head protectors for kids who do this if you're worried."

"These days I find that helping my son to calm down through breathing slowly with him not only helps him to control his reactions but it also calms me down too!"

"If the meltdown happens when you're under a time constraint, it can make matters

worse as you try to 'hurry up' the calm down. My son's mainstream school knows

that he's autistic. Recently I called them up just before "If the tantrum is school to say he'd had a bad, I calmly tell him to meltdown and I was calm down and I leave him calming him down before in his room for five or ten school - they were fine minutes. It just gives me a bit and just said take your of space as well because I time. He still arrived in know that he responds to time to join assembly, it and absorbs my just gave me a few extra tension." minutes without that added pressure. Plus he was in the right frame of mind for school.'

OUR TIP: Try to avoid the combination of stresses that cause meltdowns. Look for early signals and plan in advance some anxiety calming solutions for stressful situations.







### HOW TO BUILD A PATH TO COMMUNICATION

There are a multitude of different techniques for building communication. This article takes you back to basics. What happens when it's just you and your child? How do you start good interaction?

### INSTRUCTIONS

#### STEP 1 DON'T SWEAT IT



Inventor Thomas Edison, (who some believe was on the autism spectrum), once said that 'genius is one percent inspiration, ninety-nine percent perspiration'. Well, in the case of speech therapy, it's vice versa. You don't have to sweat to get plenty of results, you just need to know how make use of existing opportunities.

**MYTH WATCH: ONLY TRAINED SPEECH AND LANGUAGE** THERAPISTS CAN PROVIDE THERAPY. Nope. They can guide you, but you're the one who's there to spot good opportunities. Doing a little play-based therapy daily can really help.

### STEP 2 FIND THE RIGHT TIME AND RIGHT PLACE



Is your child in a relaxed, receptive mood? Be available. Watch, wait, listen and show that you're ready to connect. Just being fully 'there' will speak volumes.

Example: 'I find bath times a great opportunity for communication. As it's one of the few times he is in one place. I find he looks at me more. He is motivated by

the water and the bubbles and I use this as an opportunity to get him to communicate.

MYTH WATCH: YOU NEED A THERAPY ROOM AND A SET AMOUNT OF TIME PER DAY TO DO THERAPY. Nope. You can use your daily routine and play times to focus on targets set by occupational therapists or your speech and language therapist. It's about making good use of the time you already have together rather than creating lots of extra work.

#### STEP 3 PLAY DETECTIVE



Be Sherlock. Follow the child's line of sight. What has caught their interest? What need is motivating them? Just pause a second and allow them to motion or vocalise. Then you can supply the word. What would they say if they could?

For more verbal children, instead of asking questions, describe what they are doing. "You're pushing the car....." When they join in or offer a comment to the conversation, repeat it back. This lets them know that what they are saying is valued.

Example: I was getting nowhere asking my little boy questions about what he did after school. "What did you eat?" Silence. "Who did you play with?" Silence. Then one day he said he saw a DVD. I replied: "You watched a DVD?" and he said "Yes, it was Bookaboo." "Wow, Bookaboo!" "Yes..." and so on. No questions needed.



DIY TIP: You don't have to use an exciting toy. Stuff that's exciting in your view may actually be rather over-whelming to them. You can get quality interaction out of a 20p wind-up toy, a balloon, or bubbles.

### STEP 4

#### **BREAK THE RULES**



We're used to asking children loads of questions to encourage them with play, but demands in the case of an autistic child can lead to total withdrawal.

Let the child lead the play - then they're already motivated. You've spotted the opportunity, now don't miss the chance to DO NOTHING! Look for that little signal you're welcome.

such as the child's body or eyes moving even slightly towards you. Copy what they do. Gradually, when they're happy, you can develop the game until it's a turn taking one, by handing them toys, for instance, and then asking for one in return for your 'turn'.

Example: "My child was very fascinated by some wind-up Thomas toys but couldn't operate them himself. He watched me do them whilst I was with him, then I handed one to him. He looked at me and handed it back. "Help?" I said. Then, when we raced the toys I'd repeat the word 'race' and 'winner!' Just very simple words, reinforced over and over, and it really engaged him because we had a shared focus".

### STEP 5 BUILD TRUST



Allow the child to take the reins. To build trust you need to show your child that their play (however unconventional!) is also meaningful to you. For more verbal children, allow them to tell you what's going to happen and 'be boss'. Put them in charge of their play.

Example: "I used to spend hours showing my child how to play with the toy cars with the garage - up the lift, down the ramp etc. All he wanted to do was spin the wheels. Eventually I sat and span the wheels with him. It was at this point that I felt he truly noticed me and we were playing together!"

### STEP 6

#### CLAMBER OVER THE BOREDOM THRESHOLD



Oh, how long those minutes can seem, when you're not 'doing' anything. You haven't made a picture, there's no glitter on the floor... Give yourself permission to just be with your child. Over time, you'll paint a far prettier picture through the relationship that develops (poetic, huh?)



DIY tip 1: Be prepared to wait for a reaction, wait for them to realise it's their turn and wait for eye contact. You'll be surprised what can happen if you tolerate a little silence and stillness.



DIY tip 2: Also, take time to think about how your child is feeling in these interactions. Is he bored? Does he want you there? He may not openly show you that he wants your involvement, but think about what he would be doing if he didn't? Allow yourself to BE in the moment with no agenda.

#### STEP 7 MIRROR THE EMOTION

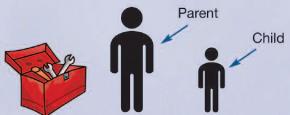


If your child is calm, mirror that emotion. If excited, mirror it. If giggly and silly, go for giggly games.

Example: "My best games are impromptu ones. The other night he was looking at a light-up toy under the duvet. Before we knew it, we had added all his light up and cuddly toys, his brother was in there too and we were having a little

tent party. I was going "Wooooooh! Spooky! Dark!" and he loved it."





Show this DIY guide to other adults who your child comes into contact with. Photocopy it if You like!





### STEP 8 GET DOWN WITH THE KIDS

Being on the child's level helps you to engage. Copy, mirror - you don't have to be creative. Believe in it, though. They can easily spot if you're half-hearted.

### STEP 9 FILL IN SOME LANGUAGE



Try just copying. Or play alongside the child if you're going for a while without much connection.

For non verbal children, think about what the child is trying to communicate through his/her behaviour - e.g. when s/he hands you a toy, say: "Mummy play," or if s/he pushes a toy away "Don't want!" The more that you

respond to the communication s/he is showing you, the more s/he will understand its impact.

For the more verbal child, start by repeating what they say, then building up to using extra descriptive words. Begin to think about adding different words without changing the meanings, such as:

Child: 'Dog playing in the puddle.'

You: 'Yes, the dog is splashing in the puddle!'

Use this time to listen to what your child says and help support their language by modelling the correct grammatical structures:

Child: "Ball down the slide!"

You: "The ball is going down the slide, yes!"



DIY TIP: By modelling what he's saying, this will help him to remember appropriate sentences. With children who read and are very visual, writing the grammatically correct response may be easier for them to process.

Example: "If I really watch what he is doing and talk about it with enthusiasm and genuine interest, he listens to what I'm saying and has learnt a lot more words this way. He is also learning that there are different ways of saying the same thing.'

IGN ALS

### STEP 10 SEARCH FOR SIGNALS

MYTH WATCH: WE'RE LOOKING FOR SPEECH. Nope. Speech and language therapy is concerned with all aspects of communication. Only 7% of communication is words.

Example: "Once I stopped waiting for the words to come and observing his non-verbal behaviour, I realised just how much my son communicates. He will pull my hand to what he wants and turn away when I get it wrong. His body language tells me what he wants and what he is feeling. Now I know this, I know what words to put in. Because I'm not overwhelming him with words unrelated to what he's communicating, I really feel that he's listening now....'



#### DIY TIP: How do I measure success?

Think of your communication work as building a house, with verbal speech as the chimney on the roof. At the moment, you're working on the foundations, a solid connection which will be a gateway for subtle non-verbal signals, leading to more quality communication.



#### AND FINALLY...

Although Edison's first quote wasn't so relevant to us, when it comes to building communication, one other saying attributed to him was highly poignant. We'll leave you with this to ponder:



"Opportunity is missed by most people because it is dressed in overalls and looks like work."

THOMAS EDISON.



To support your child's journey through childhood into adulthood our ASC specialist services include:

- Inscape House School Bridge College •
- · Community Support and Short Breaks ·
- Shared Care and full-time Residential Care •

Together we work across the autism spectrum from birth to adulthood. We provide independent diagnostic and specialist assessment, speech and occupational therapy assessment and delivery. We also provide consultancy.

> To find out more please contact us togethertrust.org.uk enquiries@togethertrust.org.uk



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LLUSTRATION BY JO PERRY, PERISCOPE STUDIOS LTD.

# WHAT NEXT? START HERE!

Here's our handy guide in a nutshell to everything you needed to know about autism, but actually didn't know you needed to know, if you see what we mean...

### For Your **Bookshelf**

- Explaining Autism Spectrum Disorder by Clare Lawrence is an easy, accessible and friendly read - a great place to start.
- **Sensory Perceptual Issues in Autism** by Olga Bogdashina. The revised version is now available. Easy, friendly read if you suspect your child has sensory troubles. The National Autistic Society also publishes a great free information sheet about sensory issues called 'Sensory'. Go to www.autism.org.uk
- Helping Children to Cope with Change, Stress and Anxiety by Deborah Plummer.
- My Brother is Different (by Louise Gorrod) and My Sister is Different (by Sarah Tamsin Hunter) - both published by the National Autistic Society, for siblings
- A Spectrum of Light: Inspirational Interviews with Families Affected by Autism by Francesca Bierens, published by Jessica Kingsley.
- Motivate to Communicate! 300 Games and Activities for Your Child with Autism by Simone Griffin and Dianne Sandler, published by Jessica Kingsley.
- It Can Get Better... Dealing with Common Behaviour Problems in Young Children with Autism: A Guide for Parents and Carers by Paul Dickinson and Liz Hannah published by the NAS (just £7.99 and pocket sized!)
- Choosing Autism Interventions: A Research-based Guide by Bernard Fleming, Elisabeth Hurley and the Goth. Published by Pavilion.

In this handy guide, research evidence for each intervention has been weighed up and the overall therapy is summarised for benefits and risks. If you want the bottom line without a lot of blurb, this is it. The green section at the back of the book, including key factors to consider when choosing an intervention, is invaluable.

Social Situation Stories by Alison Harris. Published by Special Direct – www.specialdirect.com

A collection of 48 social situation stories for teaching social and life skills to children with autism and related disabilities between ages 5 and 11. Written by a paediatric Occupational Therapist, this acts as a really good beginner's guide to preparing your child. These types of stories offer plain, simple and factual guidance on social situations to prepare a child with autism for different experiences.

■ Toilet Training for Individuals with Autism or Other Developmental Issues by Maria Wheeler. Published by Future Horizons.

Subscribers can look for books we've reviewed by searching under each issue in our online archive at www.aukids.co.uk if you like the look of a book, you can open the pdf relating to that issue.

### Financial help

If your child has been diagnosed with autism and is behind on development,
you should be entitled to the care
component of Disability Living Allowance, which is
not means tested. To be eligible your child has to take longer than average to perform daily tasks. If you get the care component of the DLA there's

a good chance you could quality for Carer's Allowance, too. This is means tested, though. Look up www.gov.uk/browse/benefits/disability for excellent advice on both or call the Disability Benefits Helpline 0345 712 3956.

Skybadger is a very good organisation offering help to the families of disabled children and has advice on benefits on its page at www.skybadger.co.uk

The NAS has published a fantastic booklet with lots of advice and guidance, called After Diagnosis. You can download it for free at www.autism.org.uk/afterdiagnosis

The booklet is available in a variety of languages. The NAS Autism Helpline offers confidential information, advice and support and is free to call. Tel: 0808 800 4104.

You can email the NAS Helpline at autismhelpline @nas.org.uk - or go to www.autism.org.uk/helpline NAS Scotland is at www.autism.org.uk/Scotland

### People to Lean on

- Ask your GP or health visitor to register you with your area's disability database so that you'll receive good local information. All areas have some sort of family information service that can put you in touch with specialist nurseries and babysitters.
- Get in touch with the National Autistic Society! They give out free leaflets and are a tremendous source of support, with helplines and guidance on every aspect of autism. www.autism.org.uk - find your nearest branch and link up.
- The National Autistic Society also runs a confidential information and advice service. Call 0808 800 4104, open Monday to Thursday 10am-4pm and Friday 9am-3pm. If phone lines are busy, you can email your enquiry - look up 'helpline' on the NAS website.
- Contact A Family is a national charity providing advice and support to parents of all disabled kids. Free helpline: 0808 808 3555 or see www.cafamily.org.uk
- Hook up with other mums in similar situations at www.mumsmeetup.com or if you join AuKids you can find out the nearest readers in your area and hook up through our website.

#### Cinema Pass

If you get DLA, apply for a CEA card (cinema pass) for your child - as their carer you will be entitled to free entry. Look up www.ceacard.co.uk or call 0845 123 1292. Most cinemas show monthly autism-friendly screenings, with the lights up, sound down, no adverts and freedom to roam! www.dimensions-uk.org/autismfriendly

More and more theatres are also turning autism-friendly by offering 'relaxed' performances of their shows, where it's quieter and the audience can come and go. Look out for them!

### **Products**

Fledglings is a charity selling specialised products: www.fledglings.org.uk or 0845 458 1124. For washable pants with padding for potty training, go to www.pshealthcare.co.uk

### Want information on a particular topic? We can help!

If you are a subscriber, go to www.aukids.co.uk and type in your username and password. This will give you access to our online archive. You can have a look at the contents of each magazine before deciding which to open. Then download online and read those extra pearls of wisdom!

#### BLUE BADGE

If your child is unpredictable, runs and can be a danger to themselves in public places, you could be eligible for a Blue Badge. Look up www.autism.org.uk and put 'blue badge' in the search box for a great guide.

### School advice

You can get independent advice for parents of kids with special needs from the National Parent Partnership Network - help in finding the right school, too: www.iassnetwork.org.uk

IPSEA offers Independent Parental Special Education Advice. Look up www.ipsea.org.uk for help on schooling, EHC plans and special needs.

Look up www.inclusivechoice.com for a free parent book on your child's rights at school.



BYEEEEE! Don't forget to join us! Go to www.aukids.co.uk to subscribe.

# EXTRA

# AUTISM ALERT CARD

Buy one from the NAS online shop for £2.50. The wallet contains a leaflet and card for emergency contact numbers. It will tell others simply and quickly about your child's condition and encourage tolerance.

### Nappies

If your child is four or above with learning disabilities you could be entitled to free nappies. Ask your health visitor.

### TOILET TRAINING

Promocon is a charity providing advice on continence. Its Children's Specialist Continence Advisors can provide support, advice and information. If you wish to speak to them, contact the helpline on 0161 607 8219. Leave a message with contact details if noone is available when you ring. Website www.promocon.co.uk