



Aukids®

Issue 44
July/August 2019

£4 where
purchased
separately

£16 annually
Available from
www.aukids.co.uk

For Parents and Carers of Children with Autism Spectrum Conditions



In a Tangle
Our expert panel
on hair twirling



**Guide
with Pride**
How to write
a Social Story™



**Many Meetings
to Climb**
Scale your mountain
of appointments

PLUS

**WIN 10 Things
Every Child With
Autism Wishes
You Knew**



 **FOREVER
MANCHESTER**

Letter from the Editors



Welcome to our
**11th Anniversary
Issue!**



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

From birth right through to adulthood, we have a range of services shaped around you:

- Special education • Flexible care • Therapy services
- Family support • Short breaks • Community support

To find out how we can help you, contact us on:

t: 0161 283 4848 e: enquiries@togethertrust.org.uk

www.togethertrust.org.uk



/TogetherTrust



/SupportTogetherTrust

Registered charity number 209782

COMM057

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

Everything you need to know in one place

www.autismlinks.co.uk



autismlinks

We were delighted to hear that John Lewis is trialling its new autism-friendly children's shoe-fitting service at key stores throughout the UK - Cheadle, Leeds, White City, Bluewater and Southampton. This is ahead of a larger roll-out which will see the initiative spread UK-wide. AuKids can proudly announce that we have been involved in this project since we approached the Cheadle store offering early autism training a few years ago. Last year, Tori and Debby trained all children's shoe-fitting partners at John Lewis in autism and gave advice on visual supports, symbols and Social Stories™.

The NAS is now taking this initiative forward to ensure that branches are consistent in their approach and that bespoke autism training continues. The John Lewis website will be highlighting the shops involved with the trial and list direct telephone numbers for booking appointments.

Some further great news: your AuKids editors have signed a contract with Jessica Kingsley Publishers for a children's book. The Autism Sundae Dessert that became so popular with readers will now make it into bookshops as *The Ice Cream Sundae Guide to Autism*, written for 7-11 year olds with autism, their siblings and peers. Best of all, AuKids' own graphic designer Jo Perry will be drawing the illustrations for the book.

The book will enable children to 'personalise' their autism, recognising that some aspects of the condition may affect them less than others. It will also highlight the 'ingredients' of autism that are positive and

encourage youngsters to think about theirs.

On another note, we are now busy preparing our '80s soundtrack for our fundraiser on September 7th in Ashton-under-Lyne in Manchester. For parents, school holidays require endless planning and preparation. So after the holidays are over, we are throwing an AuKids party especially as a 'well done!' for your hard work over the summer. It's our annual fundraiser for AuKids and we're getting some fab prizes for our raffle on the night.

Anyone who is a fan of AuKids is welcome – not just parents but teachers, friends and family! We're also hoping that SEN professionals will bring their teams along and book a table of 8 (discount available for this - ask at admin@aukids.co.uk). And by the way, if you or the organisation you work for would like to donate a prize for the raffle, we'd love to hear from you at editors@aukids.co.uk!

A word about what's inside this issue... We found that readers repeatedly ask for a guide to Social Stories™, so we have pulled out our popular feature on them from our archive for you to locate easily.

Finally, you'll notice a new logo on our front cover this issue. We'd like to say a huge thanks to Forever Manchester who have donated £1,000 to help us cover the production costs of our October (Christmas) issue. To a small organisation like AuKids this will make an enormous difference. Thank you!

Tori & Debby

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

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.

EDITORS: Debby Elley (Executive Editor) and Tori Houghton (Associate Editor)

RESEARCH AND ADVOCACY: Tim Tuff

MAIN COVER IMAGE: Oliver Billington taken by David Laslett www.manchesterphoto.com

PRINTING: R and P Printers, Dukinfield

GRAPHIC DESIGN:

 **periscopestudios**

www.periscopestudios.co.uk

Cover Star

Oliver Billington

Age 8

Lives Cheshire

Diagnosis Autism

Oliver's dad says: Oliver is a very happy, gentle and affectionate boy, especially when he has life's essentials to hand, like his iPad, a bag of apples and a bottle of milk. He has always loved being pushed on the swing or jumping on the trampoline with his two sisters. He is also lucky enough to venture out with a carer on Saturday mornings for some parent-free fun.

The 'watching cartoons exclusively in Dutch' phase was short-lived but interesting, whereas the 'Postman Pat in Scottish Gaelic' phase was rather more prolonged.

Oliver spends a large portion of his day laughing and brings a lot of joy to the people that he meets. What he is laughing at can sometimes be a bit of a mystery though - he can find humour in the most unexpected places, like videoing the end credits of Coronation Street, or watching Mr Bean cartoons played in reverse.

Once he has found something particularly amusing, Oliver likes to revisit and replay the scenario quite obsessively. More troubling compulsions have been using the mobile phone to video the inside of the fish tank, dropping wine glasses out of the window just to record the smashing sound, and posting pebbles in the drain to see if it will eventually fill up. The 'watching cartoons exclusively in Dutch' phase was short-lived but interesting, whereas the 'Postman Pat in Scottish Gaelic' phase was rather more prolonged.



Although some of his behaviours over the years have been quite challenging, and very different to those of his sisters, Oliver continues to make small steps all the time.

This calls to mind a valuable piece of advice that we received during an autism-awareness course we went to shortly after Oliver's diagnosis in 2012. We had no understanding of what the future might hold, just an underlying fear that Oliver was so different to other children his age. The speaker was Debby Elley of AuKids who talked about the importance of not comparing 'apples' (our children) to oranges (everyone else's), but to try and focus on comparing this year's apples to last year's apples. This was a real eye opener for us and is something we have tried to focus on with Oliver.

Oliver has learnt to read and write, and to do simple addition. He gets himself dressed now and is learning to brush his own teeth. These are things that we found hard to imagine only a couple of years ago.

Most rewarding is the fact that Oliver now looks to share things that he finds amusing, to try and make other people laugh along with him. We are hoping that his speech and verbal communication continue to improve, but in the meantime, we are just happy to be around him, to be woken up by his laughter every morning and to hear him sing himself to sleep with his favourite nursery rhyme every night.

I ♥ 80's

Join us for AuKids 80s Night!

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

Anyway, forget about grammar!

Celebrate the end of the school holidays and the beginning of a new term! Parents, teachers, family and friends all welcome. If you're a fan of AuKids in any shape or form, come along!

'If we took a holiday-ay...took some time to celebra-ate...'

Just one day out of life. It would be-ee, it would be so nice!

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

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

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

Fancy dress optional but VERY welcome!

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

NEW PRICE! Tickets are £25, available at: www.aukids80snight.eventbrite.co.uk

See you there!

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

New Hens for Christopher

We received some sad news in May. Just weeks after Christopher and his pet hen Gloria were photographed for our April magazine cover, a fox broke into the coop and killed all of the hens, including Gloria. Christopher's grandma died later in the same month. We were so sad for him.

AuKids decided to pay for some new hens on behalf of our readers for Christopher and his family. As we write, the new girls (Debby, Tori and Jo after the AuKids team) are being collected from The British Hen Welfare Trust. This is

a national charity that re-homes commercial laying hens, educates the public about how they can make a difference to hen welfare, and encourages support for the British egg industry. Its ultimate aim is to see consumers and food manufacturers buying only UK produced free range eggs, resulting in a strong British egg industry where all commercial laying hens enjoy a good quality life. We're sure it's a cause that our readers will get behind!

Christopher's dad Shaun, pictured with him, has been putting down fresh turf, taking down the previous chicken house and painting a new one ready for the new arrivals. The chicken wire has been re-secured, of course.

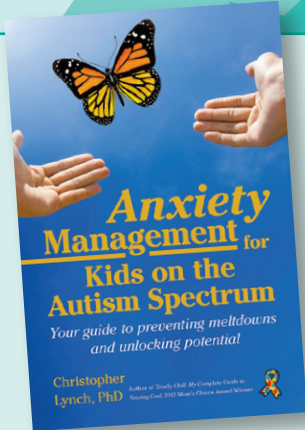
Mum Julie said: "I can't thank you enough - it is such a lovely gesture and made things a bit brighter in what has been a very dark few weeks. Please thank the readers on Facebook for all their advice and kind comments. Christopher said 'Thank you - appreciate it' - followed by lots of jumping and a very happy boy!"



Our mini roving reporter Izzy Toman took an early peek at our **Ice Cream Sundae Guide to Autism**, as part of our little testing team. Having read it, she said it was the best book she had read up till now - and since she is doing a 100 book challenge this was praise indeed! She drew her own ice-cream sundae afterwards and proudly shows it off here! We hope other kids like it as much as you, Izzy!



Reviews & Prizes



BOOK
Anxiety Management for Kids on the Autism Spectrum – Your guide to preventing meltdowns and unlocking potential

By Christopher Lynch
 Published by Future Horizons
 £16.95 • ISBN 9781941765982

Christopher Lynch is the author of 2012's *Totally Chill: My Complete Guide to Staying Cool*. This was a triumph of a book, so I was delighted that he has released a much-needed guide on anxiety management aimed at adults caring for children on the spectrum.

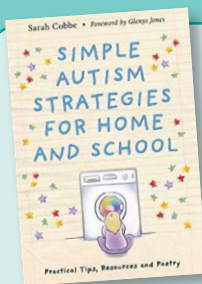
We needed a book like this. Anxiety and autism are interconnected. An autistic person living with the demands of a non-autistic society unfortunately can't avoid it. Untended, anxiety is a little like a fire, that looks pretty harmless to start with but can soon blaze out of control. To prevent mental health problems in our autistic teens and adults, carers need to help children understand and control their anxiety early on. This book will help you do just that. I completely agree with every word of advice within its 181 pages. Whether your child is six or 16, verbal or non-verbal, you'll get something from it. I would however say that it's particularly essential for teachers of children in a mainstream school setting.

Despite a distinctly uninspiring cover design (sorry, Future Horizons), this is a brilliant guide both for parents and teachers. The author, a clinical psychologist with many years of experience in this area, breaks down the five key causes of anxiety in autism (rigidity, sensory sensitivities, social challenges, communication barriers and task frustration), which he dubs the 'prime suspects'. He delves into the reasons that each is responsible for anxiety and follows up with a host of strategies and solutions specific to each 'suspect'.

The down to earth guide (which sounds like the author is speaking to you) has enough detail to give its readers a really good idea of how to prevent anxiety without getting so bogged down in technicalities that it loses your attention. There's much general wisdom here, but the book's strength is that it suggests lots of easy and workable ideas that any education setting would do well to follow.

This book is as close to an anxiety consultant visiting your school or home as you're ever likely to get and a darn sight cheaper. Thoroughly recommended.

Debby Elley, AuKids co-editor



BOOK
Simple Autism Strategies for Home and School

By Sarah Cobbe
 Published by Jessica Kingsley Publishers
 £16.99 • ISBN 9781785924446

Author Sarah Cobbe has more than 20 years' experience of working in the field of autism which includes teaching, advising and training others to support children with the condition. Her own autism spectrum diagnosis provides a unique insight and perspective conveyed via her poetry in this book.

In this book, aimed at both parents and education professionals, the author seeks to provide readers with a greater insight into the strengths, needs and interests of children with autism.

In Part One, the author explores the autism diagnosis and presentations. In chapters Two and Three she outlines possible

everyday challenges at school and home with practical suggestions on how they may be addressed.

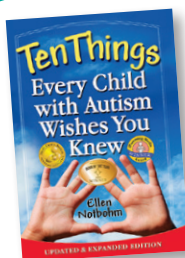
Each chapter has three sub headings; **What we can learn, how we can help and where we go next**, which provides further references and links.

The book's practical chapters make it helpful for readers to locate specific topic information as well as making for an easy read in general.

I wasn't initially sure what the short poems at the beginning of each chapter were going to add, but their relevance quickly became apparent - they offer a further perspective for consideration.

A positive and practical focus, plus an easy to read format, make this book a valuable resource for school teams and parents. It would be useful as an introduction for professionals and parents new to the world of autism.

Joanne Hibbert
 Early Years SEND specialist



BOOK
Ten Things Every Child with Autism Wishes You Knew

By Ellen Notbohm
 Published by Future Horizons
 £14.95
 ISBN 9781935274650

It is ten years since my son received an autism diagnosis and I've stumbled across useful information more by accident along our journey. I was interested to read this award-winning paperback, which is now in its third edition, having sold more than 250,000 copies in 20 different languages. The American author, Ellen Notbohm, is mother to two boys, and shares her personal experiences of raising her autistic son, Bryce.

The book comprises ten chapters, with the addition of some bonus material and self-reflection at the end. Each chapter begins with a paragraph written in the voice of an autistic child, followed by a detailed explanation from Ellen, drawing on examples of how Bryce coped with a range of scenarios.

The book is written in a positive tone and encourages the reader to switch their negative views for example 'build on what I can do rather than what I can't.' This is an important message, particularly to parents who have only just received a diagnosis for their child and may be worrying about what lies ahead.

Of course, every child on the autistic spectrum is unique and what works with one child, may not help others. It covers many general topics but for me, did not touch on some of the 'demand avoidant' challenges that many of us cope with.

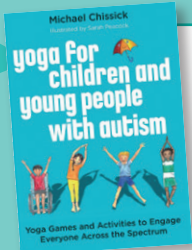
We explore the difference between 'cannot' and 'will not', sensory issues, communication, social skills, managing meltdowns and acceptance. Each chapter reinforced some of the vital information that has taken me a decade to understand. How I wish I had been presented with this book on day one! It is an excellent resource for parents and teachers, with practical support strategies.

By Julie Thomas
 Parent of a 14 year-old with Autism,
 Pathological Demand Avoidance and ADHD



WIN!

We have two copies of this book to give away. Simply send your name and address to competitions@aukids.co.uk with 'Ten Things' in the subject header no later than August 30th 2019. Winners will be chosen at random after the closing date. Please note, by entering the competition you are agreeing to the publisher so that they can send you your prize directly. No other third party will be notified of your details. Best of luck!



BOOK

Yoga for Children and Young People with Autism

By Michael Chiswick

Published by Jessica Kingsley Publishers

£14.99 • ISBN 9781785926792

The author has spent many years teaching yoga in the UK to children with autism, mostly in educational settings. He describes the book as being 'a teaching guide for everybody who has been touched by autism' and for parents who want to teach yoga to their children.

Firstly, the author explains how he teaches yoga to children across the spectrum, using lesson plans differentiated for the three main groups he identifies, but with lots of guidance for adaptation within the groups. His plans are well structured, including an opening, yoga sequence, main activities and calming.

In the second section, there are lots of illustrations and he stresses that it's not the 'quality' of the pose, but joining in and trying the pose, singing the song or 'good sitting' quietly and calmly that are most important. The yoga is based around 10 basic positions with adaptations for sitting or standing, in classrooms or a larger space. The positions are introduced during games, often with songs and there are also printed materials and songs you can download to use in the games or in a visual timetable. He ends with some case studies.

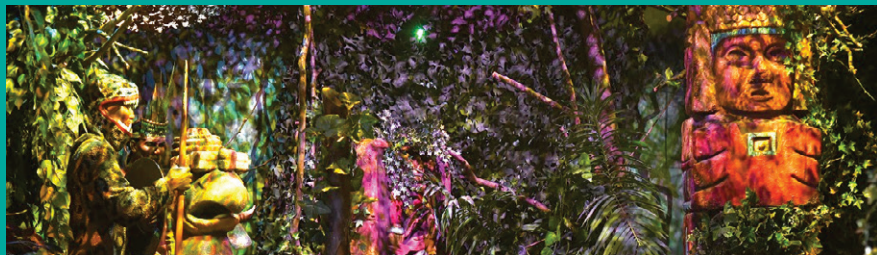
As a parent whose child has had some exposure to yoga in school and loved it, I eagerly read the book in a couple of hours, and found various parts of it I would definitely use with my son, 10, who enjoys the calming effect of yoga. I especially loved the basic positions and the relaxation ideas, particularly the 'ladybird' game.

In summary, if you're a teacher, this book is a must have for using with all students. Parents, if you are interested in trying yoga with your child, this book is a great place to start. Don't forget to show it to their teacher too!

Vicky Banford, parent reader

WHERE TO GO | Cadbury World | Birmingham, UK

Chocs Away for Cadbury Day!



We were lucky enough to visit Cadbury World for one of their first relaxed SEN sessions. First of all, a description of our family. We are a family of four, with a neurotypical 9 year-old son Patrick and William who is 7 and as well as being on the spectrum, has severe learning difficulties, ADHD, high sensory needs and is non-verbal.

The session was due to start at 9.30am and we got there early at about 9am. William is not good with waiting and there was already a significant group outside, so we went round the corner from the entrance and found a small enclave which had some ride on machines that William could clamber on and off whilst we waited.

They opened at 9.30am and the staff were friendly and accommodating as we had a short wait to exchange our tickets for wristbands. We chose to push William round in his buggy, as this is his safe place and helps us manage with transitions, of which there are plenty on the Cadbury World tour.

As you start the tour you are given some free chocolate which William indicated he wanted quite definitively so for an easy life it was 'Crunchie for breakfast'.

The first area you enter is Aztec Jungle, showing the origins of cocoa and chocolate. This had running waterfalls, (fenced off), which grabbed William's attention.

This is followed by an area with videos playing on the history of chocolate and how it is made. They are activated by walking past them. On the plus side they had holograms of people narrating using sign language, but on the negative side when all videos are playing at once it is a cacophony of noise which sent William into a meltdown.

All the staff were very helpful, accommodating and non-judgmental. There were a couple of small movie theatre areas that we just whisked through as William wasn't in a state to sit and watch. That is one of the major pluses of the tour; you can mostly go at your own pace and if there is an area that you are not getting on with, you can quickly get out.

We caught a lift up to the next area of the tour. There, you have the chance to manipulate gooey chocolate on a marble surface and write your name in chocolate. Then there is a slow ride - 'Cadabra' - reminiscent of Disney's "It's a small world".

Following that there is an opportunity to taste a small cupful of gooey chocolate with your choice of topping as a chocolate technician explains more of the chocolate making process.

Then you come to a green screen area where helpful staff allow you to choose your backdrop and props to make a memorable photo of your visit, (for extra cost of course!)

Next up, the highlight of the trip for us, the sensory room. Lots of space, lights and sounds to play with. William would have quite happily stayed in there for hours.

You then exit via the gift shop. Good luck with that!

Outside round the back there is a small adventure playground (the African Adventure Play Area) and an opportunity for 'The 4D Chocolate Adventure' ride, which is accessed via a lift. Beware, the lift ride is the start of the adventure so not good for anxious people.

The 4D ride is in a small cinema and you are given 3D glasses. The seats shake and tilt to give you the impression you are on a ride. Unfortunately, William wouldn't sit still in his seat so he missed out. I wonder if they could do some seats with harnesses?

All in all, it was a memorable morning. You should allow at least 2 hours, even rushing through many areas. The staff were welcoming, although some areas could probably do with being made more autism friendly. The highlight was definitely the sensory area. Sweet.

Barry Hughes, parent reader

Cadbury World replies:

We're pleased to have hosted these AuKids readers and valued their feedback on the relaxed sessions. We continually strive to make sure every visitor to Cadbury World has the best possible experience and we will be looking at how we can further improve the sessions in the future.



SWEET SENSATION:
William in the sensory room



“ My daughter is five and non-verbal. She is a hair twirler and she’s doing it so much lately that she is matting her hair and I can’t untangle it and am having to cut it. Is there anything else I can do to give her the sensory input she needs?” ”



Rachel Johnson (Lead Occupational Therapist) and Charlotte Ardern (Occupational Therapist) Seashell Trust.

Seashell Trust is home to the Royal School Manchester, a non-maintained special school, and the Royal College Manchester, an independent specialist further education college. Both are attended by young people with complex and severe learning disabilities.

Firstly, well done for recognising that your daughter is seeking the sensory input, it is often quite difficult to pin down the purpose of a behaviour.

We all, as humans, both seek and avoid sensory stimuli in different forms, including noise, light, touch and taste. An example of this can be nail biting - lots of children and adults bite their nails. It can be a symptom of seeking oral motor stimulation and can form a difficult habit to break.

As adults, we can recognise when the behaviour or action needs to stop, for example stopping biting your nails before they bleed. Children, generally, do not yet

have this understanding and may continue the action that gives them the sensory input they are seeking. So, sometimes it helps to try and replace the habit with a less destructive alternative.

It’s important to try to work out whether your daughter is seeking tactile input to her scalp and/or her fingertips. If she is unable to tell you, we suggest trialling a mixture of the following to see what works for her.

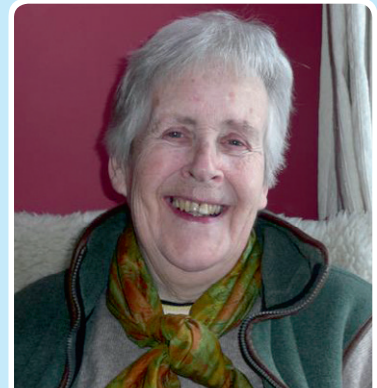
There are a large number of tactile receptors on the fingertips (and round the mouth), so people tend to seek the most input from those areas. It is likely she is seeking stimulation through her fingertips. As an alternative, try encouraging her to play with items that have a similar texture to hair such as ‘Koosh’ balls, fiddle toys, plastic string or cotton wool.

You could explore some play with hair extensions, a cheap wig or a doll with long hair. In addition to this, we suggest you also encourage her to explore different textures, as this will give her additional stimulation. Try messy play items like slime, paint, Play Doh, kinetic sand and cake mix.

To replicate the sensation on her scalp, you could try a head massager. Also, provide deep massage when washing her hair, use a firmer bristled hairbrush and for longer periods of time, or braid her hair as this could provide increased pressure to localised areas of the scalp.

Look at whether she does this more during certain activities or at specific times of day. It may be a sign of anxiety and it might be beneficial to look into strategies to support her to remain calm.

At the age of five your child will probably not recognise that she is feeling anxious and may be unable to communicate this, but you may be able to see a pattern and introduce some of these ideas in to her routine.



Phoebe Caldwell

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

My suggestion would be to try vibration and see if this helps, both on her hands and if she will take it on her face and head. Try it frequently but for short times, say five minutes per hour. You also need to look at what is triggering her need to twirl her hair so vigorously; it is almost certainly a symptom of sensory overload of one sort or another and is helping her body to cope.

I should be looking at her environment and any hyper (over) or hypo (under) sensitivities she displays. Are there times when it is particularly evident? One that is sometimes missed is when a child gets emotionally overloaded. For instance, she may be sensitive to direct speech, birthdays, praise and anything with an ‘overload’ of emotional warmth.



Jonas Torrance

Jonas Torrance has worked with children and adults on the autistic spectrum for over 35 years. He lectures nationally and internationally on the subjects of movement therapy, challenging behaviour and autism. Last year he published *Therapeutic Adventures with Autistic Children: Connecting through Movement, Play and Creativity*, published by Jessica Kingsley Publishers.

Before making an intervention, we need to recognise that a behaviour is happening because for the child, it has a function; it is useful. Once we realise this we can then recognise that if we are successful in removing the behaviour, it will very likely be replaced by another behaviour. So before we intervene we need to ask ourselves the question: *If not this, what else?*

I'm guessing that you've decided to intervene, so then let's look at what has the highest possibility of success. In order to do this we need to understand what the behaviour may be reflecting, supporting or deflecting.

Analysing the Behaviour

Movement analysis points to hair twiddling being about time and flow. In simple terms, when your daughter twiddles her hair, she feels the flow of it moving through her fingers. There is something reassuring and clear about getting

to the end of her strand, because, for her, it is a marker of time. It is her way of saying 'I am here' and then at the end of the next strand, 'I am still here'.

Now look very closely at the way that she twiddles. Does she pull hard on her scalp? Does she cover her ears? Is she precise and neat or is the movement more random or chaotic? Twiddling may well be partly about having her hands up near her head. This is common in autistic children: it's a defensive response, like a boxer who is protecting himself from the next punch. Although the twiddling may be soothing now, it might have started as an anxiety-based response.

Practical possibilities

- See if she is interested in marking time in other ways, by clapping, singing, looking at timers, baking etc.
- Introduce weight as another way of experiencing herself in time and space. For example, by bouncing a ball, tapping or stamping. You will notice, if you try it yourself, that it is very difficult to twiddle your hair while you do these activities.
- If she is pulling hard, she may need some attention on her scalp and jaw. Pressing her head can help, as can finding ways to loosen the jaw. Chewing gum is not ideal, but take note if a chewing action alleviates the behaviour, you could try other, more suitable, methods.
- At times when her hands are down, massage them, and also the upper and lower arms, perhaps with soothing oils, to help her enjoy having her arms lengthened and relaxed.
- At school, help her draw around an imprint of her own hands, then cut them out and laminate them onto her table. This is a clear place to put her hands when she needs to have her 'hands down'.



Breanne Natasha Kirkham

Specialist Occupational Therapist & Trainee Advanced Practitioner
The Carol Kendrick Centre, Wythenshawe

Firstly, it is important to try to identify why she is twirling her hair.

Have a look at what happens before she does it and whilst it's happening. Then consider the impact the hair twirling is having on your daughter and others.

It is never wise to try and stop hair twirling before looking at those points, because the hair twirling may be serving a purpose. Hair pulling and twirling can be caused by anxiety, frustration, boredom, to help a person focus or to get sensory feedback. If it's sensory feedback she needs, here are some alternatives.

Proprioceptive Feedback

is a term that refers to feedback through muscles, ligaments and tendons. Getting this type of feedback is usually calming, so helpful if a person is anxious or frustrated. You can get proprioceptive feedback through fidget items that offer resistance, like Theraputty, a Theraband, stress balls and physical activities such as pressing palms of hands together.

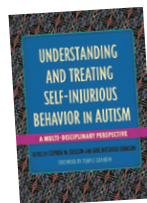
Tactile Seeking

means seeking feedback through our touch receptors (in the skin), which may happen when a person is feeling bored or seeking out extra sensory input to help them focus. Sensory alternatives may include the use of a tangle teaser fidget item, a straw, pieces of ribbon tied together, or even a small piece of curtain tassel, as this may provide a similar sensation to that of hair.

Movement Seeking

People can use touch sensation as an alternative to movement, when movement is not possible (who doesn't fidget with a pen during a meeting?!).

It is common to fidget as a replacement for movement. Try to work in more movement opportunities throughout the day, for example household chores that use the hands, like polishing, wiping, washing and sorting. These provide extra tactile and proprioceptive input.



Further information

BOOK: Understanding and Treating Self-Injurious Behavior in Autism, A Multi-Disciplinary Perspective
Edited by Stephen M. Edelson and Jane Botsford Johnson, Foreword by Temple Grandin
Published by Jessica Kingsley Publishers.

BOOK: Responsive Communication: Combining attention to sensory issues with using body language (intensive interaction) to interact with autistic adults and children
By Phoebe Caldwell, Elspeth Bradley, Janet Gurney, Jennifer Heath, Hope Lightowler, Kate Richardson and Jemma Swales. Available at Pavilion – www.pavpub.com

Trichotillomania is a mental disorder which triggers people to pull out their hair frequently. Although the exact cause is not clear, anxiety, stress, imbalanced brain chemicals, and hormone level changes are the possible causes of trichotillomania. To find out more, go to: www.trich.org/category/for-kids-teens

Also see: www.patienttalk.org/what-is-trichotillomania-why-is-this-common-for-people-on-the-autism-spectrum/

Fidgets



- Buy Theraputty at www.nrshealthcare.co.uk
- Therabands are available at Amazon and Ebay.
- Scalp massagers are also available at Amazon and Ebay.
- Gripp hand exercise balls are wonderful and very tough – get them at Amazon.
- You can get large fidget balls (koosh balls) at www.multi-sensoryworld.co.uk/products/large-fidget-ball

Maps of the Social World



Using Social Stories™ to Help Your Child Navigate Their Way

To autistic children, social skills are uncharted territory. It seems that everyone else is carrying a map, but they haven't been given one. Knowing what's expected of you in hundreds of different social situations can be terribly confusing. The Social Story™ is a simple tool that can be easily overlooked, but if you were going somewhere new, you'd take a map. By creating Social Stories™, you're doing the same for your child. Our resident speech and language therapist Tori Houghton shows you how...

What are Social Stories™?



Carol Gray

Social Stories™ were developed in 1991 by Carol Gray, Director of The Gray Center for Social Learning and Understanding in Michigan. They are written or visual explanations of social situations. For example, take going to the dentist for the first time. Someone might explain to you how you would go up to reception, give your name, wait in the waiting room and your name would be called. Once with the dentist you would have to open your mouth and so on...

You wouldn't be told how to behave, but you'd be given a verbal explanation of what to expect.

Social Stories™ are based on a similar idea, but instead of *talking* about what is going to happen, the explanation is a written one. As the famous autistic speaker Ros Blackburn has said, never assume that someone with autism knows the score. Stating what seems like the obvious may feel a bit patronising to you, but can make life very much easier for them.

When Do We Need Them?

Social Stories™ can act like a stitch in time. If you know that a small change, or a bigger one, is going to cause anxiety or stress, a Social Story™ is a good way of preparing your child for what's going to happen in a very neutral and calm tone.

Social Stories™ are also good for preparing kids for what's expected of them in totally new situations, for example going to a wedding ceremony. But they're also a great tool for daily challenges and can be used to explain what the 'rules' are for stuff like going to a public toilet or to a library, where a lack of knowledge may make them behave inappropriately or cause them distress.

Having a step by step explanation beforehand is far more effective than trying to tackle problems when you're in the middle of them – for you and for them! As a parent, it does mean thinking about a situation before it occurs and then preparing a Social Story™ to nip any concerns in the bud.

For all sorts of kids on the spectrum, it's really useful and once you've written one or two, they'll become second nature.

Why Do We Write It Down?

We know that most autistic people generally respond better to visual information. It's permanent, predictable and reassuring and can be consulted and re-read to ensure understanding.

Be Prepared!

Think of this as a compass and map for your little Scout, helping them to navigate through the confusing world of social situations. The Social Story™ explains the theory behind our sometimes bizarre social behaviours – what is expected and why. When we plan a trip abroad what's the first thing we do? Get a guide book! We read up on the kind of behaviour that can be expected in a different culture. Then we know what to expect. Overall, life is less stressful when you're well prepared.

I'm No Poet...

You don't have to be. It's as simple as writing a shopping list, just follow our step by step guide below.

So What Does A Social Story™ Look Like?

A Social Story™ About A Social Story™

I often need to explain to my autistic child what is going to happen in a social situation and what is expected of him. **(DESCRIPTIVE)**

This is like when I go to an appointment and someone needs to explain to me what to do. **(CONTROL)**

Social Stories™ are a way of describing to him what is going to happen and why in different situations. **(DESCRIPTIVE)**

Social Stories™ always contain more descriptive sentences than directive ones. **(DESCRIPTIVE)**

This is very important. **(AFFIRMATIVE)**

I will try and use more descriptive sentences in my Social Stories™ to help my child understand the world around him. **(DIRECTIVE)**

KEY - Main Types of sentences:

DESCRIPTIVE: Answers the "wh" questions and describes the situation from an objective perspective.

CONTROL: Compares this situation with a more familiar one, providing personal meaning by using the child's interests or previous experiences. You might well use the phrase: "This is just like when....."

AFFIRMATIVE: A reassuring nod to the child's anxieties - it enhances the meaning, 'this is ok'. E.g. *I might feel a little unsure about this at first. This is okay, I can take my time.*

DIRECTIVE: Usually near the end of the story, this positively and flexibly offers a response usually in the form of "I will try to....." We use the word 'try to' to allow for errors and avoid rigidity.

What If My Child Doesn't Read?

It's important to tailor Social Stories™ to the right level of understanding for your child. You can read the story to your child or s/he can be shown through a picture version. Social Stories™ only really work with children who have some understanding of language. For those who struggle, simple pictures or symbol strips are more effective.

What Makes It A Proper 'Social Story'™?

Social Stories™ follow a particular format as identified by Carol Gray. The format is carefully balanced so that the child receives gentle, clear explanations and is steered in the right direction rather than dictated to. The Social Story™ is constructed to connect with a child on their level and to avoid applying any pressure. The way that they're constructed means that autistic kids can readily take on board the information in them. Finally, to avoid confusion, they're aimed at explaining ONE thing only, not several situations or responses at once.

The Format – A Social Story™

1. Has a title, to orientate the person straight away
2. Has an introduction, main body and conclusion
3. Answers "wh" questions
4. Always uses positive language
5. Is written in 1st or 3rd person perspective
6. ALWAYS contains descriptive sentences
7. Contains twice as many descriptive sentences than directive ones – 1 directive sentence to every 2-5 descriptive/affirmative ones

8. The format is tailored to the person's level of language
9. It may include illustrations

How to Introduce a Social Story™

Depending on your child's level of understanding, it's important that they understand that it's their story. Personalise it, use examples of their interests in the story e.g. *like when Numberjack 4 is late...*, and enlist their help in making it colourful. Read the story well before the situation is going to happen and have it available for future reference.

Social Story™ Everyday Example:

Going to the Supermarket

Sometimes I go to the supermarket with mum.

I like doing the shopping with her.

Sometimes if I walk away from mummy when she's busy, she can't see where I've got to. This makes her worried, like when Numberjack Five lost Numberjack Zero when they were out and about.

Staying close to mummy in the supermarket is really important because it keeps me safe and it stops me from getting lost. It also makes mummy feel really happy and proud of me.

I will try and stay close to mummy when we are in the supermarket.

Further Information

Book: Carol Gray – My Social Stories™ by Carol Gray and Abbie Leigh White, contains lots of example stories.

Factsheet: NAS – How to Write a Social Story™. Look up www.autism.org.uk/about/strategies/social-stories-comic-strips.aspx

Websites:

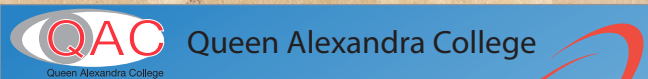
Carol Gray's website includes lots more information on Social Stories: www.carolgraysocialstories.com

Watch Carol talking about Social Stories at the Autism Europe International Congress here: www.youtube.com/watch?v=QgxH_BB4PvM

Apps:

HandHoldAdaptive has created Story Maker, an app for making Social Stories. Made for the iPhone and iPad.

www.handholdadaptive.com/StoryMaker



PRESENTS **autism central**

An exhibition of products and services for individuals, professionals and families

24 OCT
2019

9.30am - 3pm

FREE ENTRY

FREE PARKING

82 Suite
Villa Park, Trinity Road
Birmingham B6 6HE

A full programme of seminars and workshops will be available, covering topics such as:

- Mental Health
- Relationships
- Sexuality and gender
- Transition

Headline Sponsor

For further information visit:
www.qac.ac.uk/autismcentral

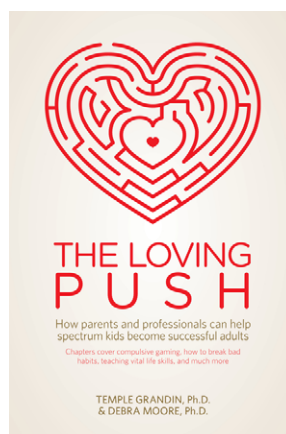
Email - autismcentral@qac.ac.uk or call - 0121 428 5041



20% DISCOUNT +
FREE DELIVERY



What's holding ASD children back,
and how can we change this?



The Loving Push
How Parents and Professionals Can Help Spectrum Kids Become Successful Adults
Temple Grandin & Debra Moore

2015 Paperback
9781941765203
£19.95 / €23.00

Order at eurospanbookstore.com with code **TWENTY** to claim **20% discount + free delivery**

We Are Capable and Deserving of an Education



About Christopher

Christopher Finnes is 20, is non-verbal and has autism, epilepsy and many motor challenges. Chris wants to do whatever he can to change perceptions of autism and intelligence. His mum found a teaching method called the Rapid Prompting Method (RPM) in 2011. Using this, Chris has been able to learn age appropriate educational topics and express his thoughts by pointing to a letter board. He has surprised everyone with his intellect and deep thoughts.

Chris's mum Sue says that outwardly, he appears inattentive, obsessively watches 'baby' DVDs and likes having nursery rhymes sung to him. She adds: 'We now know he is highly intelligent and believe there are many other people like him. It has not been an easy process and he still has many challenges, but he has always expressed that he would like to help others.'

Chris was delighted to be nominated for the Leaders List award held by the charity Dimensions in 2018. He has already helped to change the lives of many children and adults who were previously underestimated in terms of their intelligence.

The following article was produced by Christopher for AuKids using a letter board held by his teacher.

Firstly, I would like to draw your attention to the common misconception that people with autism have learning disabilities. This is incorrect and comes from the fact that most of us have limited verbal and motor capabilities. Language, motor and speech are all different parts of the brain therefore this means that you can think and understand without being able to

show it. How did society get it so wrong?

Once you can understand this then the real question is why not educate autistic people age-appropriately?

.....
"How would you feel if you were taught easy concepts, that you understood the first time, over and over again?"
.....

Everyone has the right to learn and find their passions. Everyone has the right to receive stimulation and converse in a sophisticated manner. Everyone should be given the opportunity to engage in important issues that affect them and others. Everyone should be treated with respect and belief in their intelligence. This way would be extremely beneficial for all involved.

So many autistics feel that they must be stupid because of where the content is pitched. How would you feel if you were taught easy concepts, that you understood the first time, over and over again? After a while you would realise that people thought you were stupid and then you would try to improve your motor skills so you could demonstrate your ability or you'd get bored and switch off. This is enormously frustrating for autistics who are desperate to learn new things. Everyone would do better if we could work at the person's age.

I would like to also address how to teach age appropriately when an individual needs help in responding.

I understand that teachers look to the student to assess their learning at points during the lesson. This is mainly done by the teacher assessing a student's motor skills as if this could show the students true mental ability. E.g. They may ask the student to pass them certain amounts of objects to assess their understanding of quantities from one to ten. However the students may not be able to physically show that despite them knowing. Therefore it is best not to make judgements based upon the motor skills alone.

I suggest the following:-

Firstly talk to your students as you talk to anyone. Respect goes a long way.

Secondly, start to read to your student. This will demonstrate that you believe they are capable of taking on new information. You then need to consider how to help your student learn a new method where they can learn how to show what they know. I would recommend the Rapid Prompting Method.

This method can help a person become more purposeful while learning interesting things. I built my motor skills by practising key words from the lessons. In the beginning I needed training to help me touch the correct letters on large stencils and alphabet boards. I had continuous prompts that included gestures, verbal directions, lots of encouragement and I also needed the pencil - this reminded my hand of what we were doing. Over time I was able to spell words independently and this meant I could start sharing my own thoughts and opinions.

Education was the tool that helped me to change my life. Learning and building on my skills each day means I am able to do more than before. I am improving in some way all the time. It just starts with the knowledge that we are capable and deserving of an education.

Further information

You can read more about Christopher and his award at this Dimensions site: www.dimensions-uk.org/get-involved/campaign/leaders_list/christopher-fannes/

Christopher has given his mum Sue permission to share videos of their work together on her YouTube channel. Sue's Facebook learning group is called Unlocking Voices Using RPM. You can also find out more at www.unlockingvoices.com

A note from AuKids

We wouldn't be the magazine that we are if we didn't add a little information on the Rapid Prompting Method to help you evaluate whether it is suitable for you or not. The National Autistic Society has given us a link to this review: www.doi.org/10.1007/s40489-019-00175-w which they report is the most comprehensive and objective account of RPM so far. The report says that caution is required as there is no research evidence to date to prove that the system works.

The difficulty here is that research on this technique is very hard to do. RPM requires proper training to administer and many hours of dedication. In addition, results are dependent on the nature of the person you are helping and the skills of the teacher in being able to adapt the teaching method to the child. It is advisable to see a trained RPM teacher to get started correctly and learn how to tailor the approach to meet your child's unique needs.

As with any intervention, AuKids would advise that you read up thoroughly beforehand and let your child guide you by their own reactions.

Stopping Those Little Interruptions

By Debby Elley

When my son Bobby was nine and in primary school, he went on an educational trip to the Merseyside Maritime Museum where the class visited a Titanic exhibition. The woman presenting their classroom session was dressed in Edwardian costume and determined to act the part, so when Bobby repeatedly piped up as she was in mid-flow, she fixed him with a stern gaze and sharply said: 'That's two strikes. Three strikes and you're out'.

The class held its breath and waited for a meltdown. Thankfully, there was none. Later, our Edwardian teacher was informed that Bobby had autism and she was far more understanding. Bobby, now 15, remembers: "She was too enthusiastic. And I had a thought that was like a bomb about to explode!"

When it comes to interruptions, as with all autistic behaviour, it's not enough to ask *How to do I stop that?* The better question is *Why do they do that?*

Here are 10 possible reasons:

1 Fear That the Thought Won't Stay

Thoughts made up of words rather than pictures can easily float away. For an autistic person, retaining them may be difficult.

2 They're Anxious

Have you ever heard an autistic child interrupt by asking the same question repeatedly? The temptation is to reply: 'I've told you already!' This repetition is caused by worry; best to address its cause.

Our Favourite Joke

Knock knock.
Who's there?
The Interrupting Sheep.
The Interrupting Sheep w...
BAAAAAAA!

3 Self-Regulation

A thought might lead to excitement and autistic people can have trouble with self-regulation, that is keeping themselves calm. Speaking the thought out loud is a way of self-regulating and ridding themselves of that excitement and energy. Even if they know it's not strictly the right time, holding back is hard.

4 They've Heard a 'Hook'

When new information is coming in fast, it's hard to process. Sometimes one word or phrase can act as a 'hook' that links to a child's very familiar experiences (for instance it's a word that makes them think of their favourite video game). When that happens, it's almost a reflex to vocalise and what you hear may take the form of echolalia (repeating something word for word).

5 You're on a Different Track

Autistic people feel less anxious when they are in control and this relates to conversation as much as to anything else. Conversations are like train tracks and if you change track too quickly by starting a new subject, an autistic person may find listening and processing that new information quite hard. Interruptions can be a person's way of forcing you back onto their 'track'.

6 Emotional Overload

As Bobby said earlier, he interrupted Edwardian lady to stop himself from getting emotional overload from her enthusiasm. A presenter usually expects their enthusiasm to transfer energy to their audience. Autistic people are like emotional sponges – when they drink up too much of this energy it can overwhelm them, since they struggle to regulate these emotions.

7 You're Telling Them Off

This is a different kind of energy, but autistic children can have difficulty in separating their own



emotional states from yours. This is why it helps to keep calm. If your voice is raised, they simply absorb your energy state and will give it right back to you – and then some! By the way, autistic kids aren't alone with this one!

8 Volume Regulation

Children with autism sometimes need some training in the volume of their voice, learning which situations require a whisper and which require normal volume. A terrific book for this is 'The Incredible 5 Point Scale' by Kari Dunn Buron and Mitzi Curtis.

9 They Don't Recognise Rhetorical Questions

Speakers and teachers often use rhetorical questions in an effort to make their audience think. Socially, it's quite a subtle skill to pick up on a rhetorical question and something autistic children may have to learn to recognise.

10 They're Not Aware They Did it

Sometimes kids with autism can't separate internal dialogue from an external one. They weren't aware you heard it!

What can we do to help?

1 Explain what interrupting is

Don't assume an autistic child will know that an interruption is rude. Explain that interrupting someone makes them feel that they aren't being listened to and can make them feel angry or upset.

2 Help them to remember

Ask your child to make a note of one word on a piece of paper that will help them recall what they were going to say.

3 Teach them to interrupt politely

Teach your kids phrases to say before they interrupt, such as 'Can I just stop you for a moment?' 'Do you mind if I say something here?' or 'Can I interrupt you for a minute?' It will make interruptions more palatable, but make sure they know they can't use this on a speaker in public (unless they're on Question Time!) They could even say 'Remind me to tell you about....' and then they won't have to remember themselves! Bobby developed his own way of doing this when little: 'Er...PAUSE?!'

4 Make turn-taking physical

If you are having a serious discussion and want them to listen, agree that the person holding a special toy is the one whose turn it is to speak. Pass the toy between you and honour the rule of speaking and listening when it's your turn.

5 Flag up changes in conversation

Saying 'I'd just like to talk to you about your bedroom...' creates a mental flag that helps the autistic listener to orientate themselves towards the new subject and gives them time to adjust. Don't give too much information all in one go without checking that they've understood along the way.

PUBERTY

Don't wait for it to hit!



Amid fighting for a diagnosis, finding suitable education and other responsibilities, puberty may be the last thing on your mind. But it's essential to prepare your autistic child for puberty so that when it *does* happen it isn't frightening. Here's some key advice from expert author Kate Reynolds.

Well, surely this isn't necessary? You may think that your child...

- Will ask questions about sexuality or relationships, as non-autistic children might.
 - Learn like typically developing children in school. However, this is often through friendship groups, which autistic children may not have.
 - Won't become sexual, a perception which is heightened when children play with toys for young children or continue to enjoy 'U' films well beyond the time that others do. This is usually due to their predictability and the feelings of security those toys offer, though, rather than an indicator of lack of sexual feelings.
 - Isn't mature enough or understands at a level below their chronological age. Although learning may need to be adapted, a 'mental age' doesn't mean that relationships and sex education is unnecessary.
 - Is non-verbal and therefore won't understand those concepts. They can, if taught in the right way.
 - Will become sexual if they discuss relationships and sex.
 - Won't have sexual relationships, marry or have children in future.
- You might also feel that you lack the confidence, knowledge or resources to tackle the subject.

But make no mistake, your children will enter puberty, regardless of whether or not you talk about it.

How soon is too soon?

It's difficult to be too soon in teaching the basics of relationships and sexuality. I'm not talking about the mechanics of sex or sexually transmissible infections, but age-appropriate learning. You can start with the basics of what are private places, private body parts and private talk, personal space and appropriate touch.

Top Tips to Start

• PRIVATE OR PUBLIC?



Start talking about being in 'public' places when you're at the shopping centre, cinema or library – autistic children learn best by being shown what they mean. Point to your own or your child's bedrooms as being 'private'.

Change nappies or have your child use a potty in the toilet rather than in a 'public' place such as the living room – and reiterate that you're in 'private' in the lavatory. If you start off in the appropriate place, your child won't have to encounter a change later on.

• THE RIGHT PLACE

Change nappies or have your child use a potty in the toilet rather than in a 'public' place such as the living room – and reiterate that you're in 'private' in the lavatory. If you start off in the appropriate place, your child won't have to encounter a change later on.

• MIND THEIR LANGUAGE

Reinforce that talking about puberty, relationships or sex is 'private' and should be discussed with certain people such as parents, teachers or very close friends. This helps prevent the all-too-common complaint of parents that their autistic children loudly make embarrassing announcements!



• LEAD BY EXAMPLE

Cover up from the bathroom to the bedroom, showing children that private parts are covered when other people are about. You can support this with symbols.

• HERE IS OKAY!

Don't stamp out sexualised behaviour or be cross about it. It isn't 'inappropriate' – it's behaving sexually appropriately, but in an inappropriate place. Once you've taught public and private places, you can simply give them the right guidance.

• ACCURATE LABELS

It's important to name the private body parts using their 'proper' names as you would with any other parts of the body. This will help your child be clearly understood whatever their setting.

• SIGN LANGUAGE

Symbols can also be used to visually indicate privacy, such as a red circular sign with the words 'Private Time' or just 'Private' on it, which the young person can stick to the outside of their bedroom door. Private time doesn't have to be sexually exploratory time; it may be the time a child chooses to be alone.



• KNOCK, KNOCK

Teach your kids to knock and wait for an answer from the bedroom



Kate E Reynolds is a single mother to two teenagers on the autism spectrum. She has written nine books mainly about aspects of relationships and sex education, published by Jessica Kingsley Publishers. Kate runs workshops for parents and speaks at national conferences.

www.autismagony aunt.com

and show them the same courtesy in return. Even if a child is non-verbal, you can still knock on their door and pause before checking if it's okay to go in. Respect the 'private time' of non-verbal children just as you would with a verbal child, otherwise their boundaries won't be accurate.

• **GREETINGS**

Talk about and practise different ways of greeting different people in their lives e.g. kiss on lips/hug/shake hands/high five/wave. Have all guests to the house and family members follow these rules.

• **WATCH AND LEARN**

Television programmes may provide a way of talking about relationships and emotions. Autistic children may need clear explanations of what is happening and opportunities to discuss consequences of what they're watching and how different characters might view what's happening. Some children may benefit from websites (assuming you vet them first) and books.

Building up to it

If you wash your child in the bath and they have no learning disability, stretch their capabilities as they get older and start to teach them how to do it themselves, so that by the time they get to puberty they'll have some privacy.

Both verbal and non-verbal children can benefit from a visual timetable to show them self-care routines. Start by asking them to predict it for you 'What's next?' and then hand them the flannel. Gradually you can reduce the amount that you do for them.

If you have an occupational therapist, they may well advise you on this or even create a timeline for you if you're lucky!

Does your child routinely sit on others' laps at 8 years of age? Think about the type of routine behaviour that may no longer be appropriate when they reach puberty and start adjusting early to give them time.*

Why bother with these 'rules'?

People have different family rules about privacy and some won't appreciate this advice or feel that it's intrusive.

As you read this, have a think about what your child does today, and how that might seem in the future. Other children instinctively develop a sense of self and others and a need for personal space, when they start to close doors in bathrooms and resist interruptions by family members.

Non-autistic children start to prefer bathing alone and may start wearing towels from bathroom to their own bedrooms. In personal care, children begin to develop a sense of privacy and tend to withdraw from others' washing them.

These instincts are often missing in autistic children, and they do rely on parents to give them more definite guidance.

established sexual behaviours and understand the social rules of sexuality, but consistency in messages across all family members, friends and schools will help them. Remember to liaise with schools – if you have an issue at home, they probably have the same at school.

Remember, it's all in the preparation – so don't wait for puberty to 'hit'!

*A note from the editors

Non-verbal children who have learning difficulties often use touch as a form of communication and that's not to be discouraged. It's important to be sensitive to sensory needs whilst working on appropriate touch. Rather than take this away, guide a child gradually towards the kind of affection that you'd be happier for them to show yourself and others outside the home as they grow. Occupational Therapists can often help.

Our AuKids team member Tim used to rub his friends' arms when he was anxious. We found that a small beanbag gave the same sort of tactile feedback and was better when he was out and about. He's learnt to use this instead.

Further Reading

Sexuality and Safety with Tom and Ellie: (What's Happening to Tom/Tom Needs to Go and Things Tom Likes): Three books written for boys (Tom series) and girls (Ellie series) by Kate Reynolds, with friendly and frank illustrations giving open and unambiguous advice about changes in puberty, going to the toilet in private and masturbation.

What are...relationships? A book for young people with autism, developmental and intellectual disabilities by Kate E Reynolds and Jonathon Powell, published by Kate Reynolds Limited and available through Amazon.

What is...personal space? A book for young people with autism, developmental and intellectual disabilities by Kate E Reynolds and Lucy Pulleyblank, published by Kate Reynolds Limited and available through Amazon.

Asperger's Syndrome and Puberty by the girl with the curly hair (The Visual Guides) by Alis Rowe, available through Amazon.

The Autism-Friendly Guide to Periods by Robyn Steward, published by Jessica Kingsley.

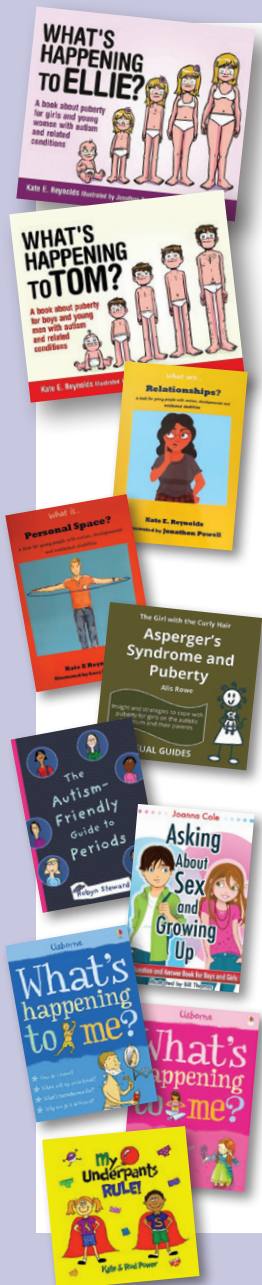
Asking About Sex and Growing Up – A Question and Answer Book for Kids by Joanna Cole for ages 8 and up www.harpercollinschildrens.com

What's Happening to Me? (Boys edition) By Alex Frith and **What's Happening to Me?** (Girls edition) By Susan Meredith, both published by Usborne.

My Underpants Rule by Rod Power and Kate Power - a great, friendly book which helps to safeguard and generate a good level of awareness in young children of all ages without frightening them.

How late is too late?

It's never too late to start. It may take longer for autistic young people to unpick



BACK TO SCHOOL?

Use code "Aukids" at checkout for **FREE** Postage & Packaging at chewigem.co.uk!

 **chewigem**
for the need to chew

A Meeting of Minds



Getting the best out of appointments

If you're reading this magazine, there's a very good chance you will have attended some sort of meeting about a child recently. Meetings are one of the key vehicles for positive change in autistic children's lives, yet it's rare to find advice on how to get the best out of them. Whichever side of the table you're on, managing an education or healthcare meeting effectively can mean the difference between going nowhere and getting real progress. AuKids co-editors, a parent (Debby Elley) and professional (Tori Houghton), used combined personal experience to write the following advice with both parents AND practitioners in mind.

1 Imagine You're Paying for it

If you were seeing a solicitor and paying for a meeting, you'd be absolutely focused on its outcome. School and health meetings that we don't pay for can easily drift without the same momentum. They're called 'catch-ups' or 'updates'. You're still giving up your precious time to attend them, so think about what you want to achieve beforehand, even if it's just to be better informed on something that concerns you.

2 The Story so Far

From a parent perspective, it's hard to interrupt when something is being explained that you already know. From a professional perspective, making assumptions can mean giving the wrong advice and destroying trust.

Take a moment at the beginning of the meeting for both sides to outline your understanding of the situation.

For professionals, it might look like this: "So, I've read my notes, but I'd like to hear from you where you feel we're up to so far".

For parents, it could be that you sense things aren't taking the right path from the outset. If so, politely ask: "Can I just outline where we're up to so far and what I'm hoping we can discuss today?"

Insisting on a clear picture from the start prevents agitation at crossed wires, or when old ground is being covered again. It helps parents to be heard and it saves time.

3 Set Realistic Goals

Outline and agree what you want to get out of the meeting and write it down. For a professional, making a note builds confidence that you're listening. For parents, to write this down can be a handy way of keeping you on track, bearing in mind there isn't unlimited time and there's an understandable tendency to veer off track when you're talking about your favourite person! It serves as a reminder of what you've got to do in order to move things forward.

4 Check The Temperature

There is a technique used in sales to 'bring people with you' and it's simple. It involves checking someone's feelings about what you're saying instead of ploughing ahead. So every so often, a professional should ask: 'Are you okay with that?' or 'How does that sound?' Check the emotional temperature. Parents can also ask 'What do you think about my suggestion?' to check that your ideas aren't unrealistic and are being considered. Asking for other people's views is central to collaboration. Ploughing ahead without them will certainly air your feelings but it won't get anything done.

5 Check Understanding

PROFESSIONALS: There's one thing that parents really hate and that's when you adopt a 'one size fits all' mentality, talking to a well-clued up parent in the same way as you'd address someone who hasn't a clue about the subject matter.

Always check what level you're working at. "Are you familiar with this or would you like me to explain as I go?"

Give the parent the opportunity to tell you what they know already. It can be a terrific waste of their time and yours if you start at the beginning when the parent doesn't need to recap.

PARENTS: if professionals do start explaining at a pace that's too slow, don't just nod vigorously, say 'It's okay you don't need to explain, I'm up to speed on that,' or similar.

Depending on the meeting, parents may well in some instances be more clued up on a situation than professionals. Professionals, don't be defensive about this, you're not expected to know everything. Your job is to support and collaborate, so the most important thing is to listen. The best professionals are secure enough to say 'Well, you've taught me something here!'

One of Debby's most successful meetings was with a primary school teacher who said: 'Look, I'll admit, I don't know much about autism. So please help me out on what to do....' They then discussed problems and solutions together.

Debby says: 'It was so refreshing. It was so much better than a teacher blundering through and pretending they knew all the answers. Parents don't expect professionals to know everything, it's more important that you can work with them.'



Tips

Has the meeting broken down? You've possibly met with the wrong person. If 'hands are tied' then you need to meet with the person who can untie them!

Invite opinions, so rather than 'I think we should...' you could say: 'I've an idea about this, what does everyone else think if...?' If you've allowed others' ideas to be contributed to a meeting, you are more likely to have your own put into practice.

Refusals, disagreements and personality clashes? Bring someone 'neutral' with you to the meeting. They can diffuse an uncomfortable atmosphere and get more progress.

If despite your best efforts a meeting isn't collaborative, note the specific obstacles and use it to put forward the case for meeting with someone else.

Everyone likes recognition and is motivated by it. 'I really appreciate the effort you're putting into this' leaves people with a positive energy that translates into action.

Finally, this article assumes that those meetings are being honest and open in addition to being prepared to listen. If you feel that someone is being dishonest with you and refuses to hear you, collaboration will inevitably break down. Seek impartial professional help to attend meetings with you and to decide on what action to take.

6 Use Neutral Language

Meetings where blame is being laid at someone's feet usually don't get very far. You may win the battle but lose the war if you can't build a decent strategy together. Talk about 'situations' and in factual terms about causes of those situations, focusing on what would HELP rather than what (and who) has HINDERED.

Focus on what should be done from this day forward. This is incredibly difficult if you're feeling emotional and angry, but it's the only way to generate positive change.

8 Acknowledge Emotions

So many conversations end up stilted because we are in a 'meeting'. But if you have emotions which are governing your reactions and approach, parents need to openly and bravely state what those emotions are. Why? This stops those feelings from 'leaking' out during the meeting and being unhelpful. So instead of hinting all the way through a meeting or adopting an aggressive stance, say it: 'I feel disappointed that nothing has happened so far and I feel really worried about what's going to happen without progress'. A lot of our anger as parents is based on fear and worry for our children and it needs to be communicated properly and acknowledged.

However, there's nothing quite so frustrating as people acknowledging these emotions, seeming very sympathetic and then doing nothing about them. So if you're a professional you've got to be honest about obstacles and share suggestions about overcoming them.

A note for either side, if you are finding a person difficult to read, ask them how they feel about the problem. If their body language states that they are disagreeing but they're not saying anything, openly address it: "You don't look very happy with that?"

9 Keep It Positive

Mentioning the things that are going well and the fact that parents are proactive in attending meetings will help everyone keep buoyant: 'Thanks for coming and I've really appreciated your input' doesn't hurt.

Tori always acknowledges the things she really loves about a child in a meeting. "It's so important that parents feel they aren't 'just another client' to you," she says. "Maybe parents are looking for huge gallops ahead, so sometimes it's my job to help them focus on the small steps that are bringing us towards that point. As a speech and language therapist I see these very clearly and it's my job to point out the significance of those steps".

7 Avoid Jargon

Parents in 'clued up' or 'fight' mode sometimes use jargon to prove they know what they're talking about, especially when they feel they're being patronised or ignored. Professionals may use jargon without realising it, or may fall back on it if they're feeling threatened. The trouble with jargon is that you may both have a different interpretation of it.

If you're a parent, please don't allow an unhealthy imbalance of power to persist by allowing someone to use jargon. Don't assume you're being silly. Instead say: 'Please can you tell me what exactly you mean by that term?' Using jargon or abbreviations is very dangerous, as people assume you're speaking the same language – often you aren't.

Someone who knows what they are talking about should be able to explain it in simple terms.

10 Sum up

At the end of the meeting, sum up what's been agreed – both parties. If you're a parent, there's no harm in asking for a quick summary of who is doing what for your records, it focuses both sides on action and firmly places responsibility on who's to take that action, whether that's one or both of you. Action points should also have an 'action by' date on them to keep momentum going. If you don't feel that one meeting has been enough, include making a date for another in your action points at the end, don't leave feeling short-changed.



The Last Word

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

Pokémon

A World They Can Understand

It's not that I wasn't looking forward to seeing Detective Pikachu with Bobby's local Pokémon fan group. It's just that I didn't have high expectations of staying awake for the next two hours.

But as is often the case, the things you look forward to least often turn out to exceed your expectations and Detective Pikachu turned out to be an unexpected revelation.

Part of the reason it captured my interest (other than my pseudo-fan delight at recognising a Bulbasaur) was that it gradually became clear to me why Pokémon are so popular among autistic people.

I had originally believed that this was down to the simple pleasure of collecting stuff. After all, if you combine making a collection with playing a console game you've already ticked two boxes for most of the autistic kids I know.

In fact, Pokémon's inventor, Satoshi Tajiri, was himself autistic and loved to collect things. The story goes that as a child he couldn't hunt for insects because he lived in an urban setting, and so invented Pokémon for youngsters like himself so that they could have the satisfaction of collecting creatures.

Pokémon isn't just a small collection, either. With 807 of them, those who are most likely to excel

at the games are people with great attention to detail and good factual recall. Ring any bells?

These reasons, combined with the predictability of their evolved states, led me to imagine that autism and Pokémon were a match made in heaven.

I thought I had that one sorted.

It turns out, however, that there is even more to it than that.

Detective Pikachu has a number of touching themes, but among them is one that struck a particular chord with me. Pokémon choose their human trainers, and they can't be caught unless that trainer has some psychological understanding of them. Added to this, each of them have very different qualities. Some supposedly weak ones have excellent special powers but they're only useful in specific situations.

I started to think of Pokémon as children with autism, who could only evolve with an understanding trainer at their side - someone who was aware of those strengths and weaknesses and could put them into situations where their skills were most useful.

My mind went into overdrive when a Psyduck appeared - a yellow platypus that happens to be a total stress-head. If it isn't constantly

soothed, the Psyduck's stress headache builds up until it sets off an actual explosion. Then it feels better.

"Blimey!" I thought. "That's a meltdown!"

Possibly I should have stopped there, but I was half way through my mental thesis and I had a further theory.

It occurred to me that if you lack Theory of Mind - in other words you struggle to see others' perspectives and guess their

motivations - understanding Pokémon just could be your path to enlightenment.

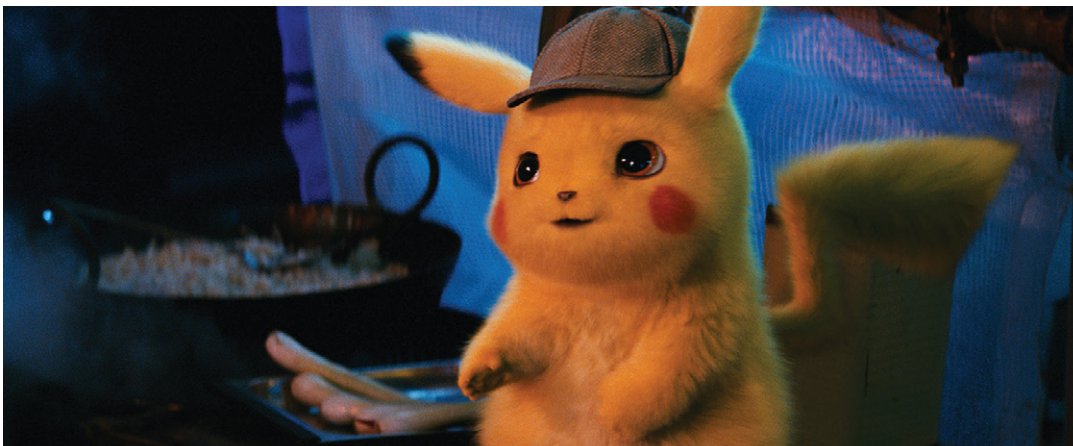
These creatures show their very obvious differences on the outside and their key personality characteristics are reflected in their appearance. So, this is a world in which others' behaviour and responses are both predictable and easy to understand. This distilled version of humanity is surely a brilliant training ground for understanding other people. Even if we can't show our characteristics on the outside, we all have different combinations of them, just like Pokémon.

So, next time we hit a 'people' problem, Bobby and I will chat about a Pokémon with a specific characteristic and see if we can find an answer based on his understanding of what makes Pokémon tick. It might work, it might not.

Anyway, I put all this to Bobby and he considered my world-shattering philosophy.

"Maybe".

I think I'll have a lie down.



Sponsored by




Want to sponsor us? Step right forward. Write to editors@aukids.co.uk