

# Aukids

Issue 25  
Autumn 2014

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# Letter from the Editors

Debby    Tori



## Welcome to our Autumn issue!

## Love Aukids?

Get the T-shirt to go with it!

Plus the hoodie, beanie hat, cap, school bag, pump bag, apron and even teddy bear!

The Aukids clothing range carries a selection of slogans dreamt up by the magazine team and designed to inspire tolerance and positivity! Quality clothing at fantastic prices made by our friends at [www.finsdesignandprint.co.uk](http://www.finsdesignandprint.co.uk). Order online. Kids' t-shirts for £8 and kids' hoodies for £14. Adult sizes also available.

A BIG thanks to Fins Design and Print for giving a percentage of each Aukids sale to our magazine.



[www.finsdesignandprint.co.uk](http://www.finsdesignandprint.co.uk)

We're already into autumn and before we know it Christmas will be upon us. Don't forget that you have our archive for inspiration here. In Issue 2 we gave tips for getting through the new routine over the season to be jolly (clue – start marking the calendar now) and there was a good gift guide in Issue 13. As the chill sets in, don't forget an Aukids hoodie makes a great present – [www.finsdesignandprint.co.uk](http://www.finsdesignandprint.co.uk) have the full range, with a donation of all sales going towards the magazine.

We're delighted to tell you that once again Tori and Debby are on the road, giving a seminar titled Positive Parent, Positive Professional at the National Autistic Society's Autism and Communication conference at the Hilton Hotel in Reading on November 25<sup>th</sup>. To register go to [www.autism.org.uk/conferences/communication2014](http://www.autism.org.uk/conferences/communication2014)

Our talks include a number of fun visual demonstrations to help our audiences to learn more about autism. We will be putting the best bits on YouTube and will give you updates through our social networking pages.

Has your child come a long way in a year? Stories for our readers' page are always welcome, so share those heart-warming moments with us and email the usual address. In this issue we champion some unsung heroes – teaching assistants! We've shared some of their best practice, but if your child's TA is a wonder and has some ingenious ideas then please share them

with us, too. If you aren't on email, then write to us at Aukids mag, PO Box 259, Cheadle, Cheshire SK8 9BE.

We are aware that many of you enjoy AuKids enough to subscribe year after year and we're working to update our PayPal system so that you will be able to have the option of automatically renewing (unless you decide to opt out). Keep updated on Twitter and Facebook.

Thank you for reading in 2014 – we'll see you in the New Year!

*Tori & Debby*

e-mail: [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com)

### CONTRIBUTE TO AUKIDS!

- In our January issue we'll be publishing our annual round-up of autism events around the country for 2015. If you'd like yours to get a mention, email it to us at [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com) no later than December 1<sup>st</sup> 2014.
- Do you have twins with autism? Would you like to contribute some of your experiences to a feature we're writing? Write to us at [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com) with a photo of both of them and we'll respond with some questions for you to answer.

### COMPETITION WINNERS FROM ISSUE 24:

- Disappointment Dragon winners: Helen Wilson, Barnardo's ASC Service, Wigan; Tony Forrester, Shropshire and Amanda Ayres, Cheshire.
- Broly Sheets winners: Joanne Dorasamy, Bedfordshire; runner-up: Paula McClinton, Northern Ireland.

Want a banner on our website? Prices are just £100 (half size) or £200 (full size) per quarter. Contact [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com) for details.

## Things have changed a bit since 1975. So have we.

But our children and young people's services have always been about what's best for them. Providing the right place and the right support to succeed in achieving the best outcomes, even in the most challenging circumstances.

Our schools and colleges offer specialist, flexible education and care for young people, all of whom have complex needs including behaviour that may challenge and a learning disability, often in association with autism.

Visit our website [www.hesleygroup.co.uk](http://www.hesleygroup.co.uk) to find out more about our services for young people or call us on Freephone 0800 055 6789.



Established in 1975, Hesley Group, through its schools and colleges support 8 to 25 year olds with a highly experienced and expert multidisciplinary educational, care and therapeutic staff resource, in high quality purpose built settings. We're focused on positive outcomes and progress towards sustainable independence.



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EDITORS:  
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PHOTOGRAPHY:  
Front cover photo taken by David Laslett at [www.manchesterphoto.com](http://www.manchesterphoto.com)  
m: 07918 155362

PRINTING:  
R and P Printers, Dukinfield

GRAPHIC DESIGN:  
 **periscopestudios**  
[www.periscopestudios.co.uk](http://www.periscopestudios.co.uk)

AuKids is published by AuKids Limited, PO Box 259, Cheadle, Cheshire SK8 9BE, company number 7413180.

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AuKids magazine, Autumn 2014

## Celebrity SPOTLIGHT



**Mckenzi Whincup**

**Age:** 5

**School:** West Wimbledon Primary School

Mckenzi attends the autism base at West Wimbledon Primary School which is called Treetops. He joined Treetops in September 2013 and has gone from strength to strength, and we definitely made the right decision on the provision for his education. Mckenzi enjoys going swimming and horse riding every week and looks forward to going to school and especially likes to see his friends. Mckenzi recently told me that Lilly is his best friend at school, although he

**I enjoy:**  
Swimming  
and horse riding

gets on with everyone. He makes the teachers laugh and smile when he says 'Good morning' and tells them they need a haircut!

Mckenzi recently took part in a play where he played the fox in *The Gingerbread Man*, which is something he would never have done before. Every day that Mckenzi does something that he has never done, it puts a smile on our faces and we feel so proud of him. Getting the diagnosis of autism was a relief as we suspected he had autism or ADHD and it was just a relief finally to be able to get the help and support we needed for Mckenzi as well as ourselves.



London Underground Tube map and is a great tourist guide for everybody wishing to visit the capital! He's able to tell people exactly which line to take and where to change stations.

William also loves football, recently joining our local disability team Warwickshire Warriors.

He has a great sense of humour. His latest is telling people that he can't eat something, or he has to have a go first, because he is autistic...

His dislikes include having his hair cut and sleeping.

William has a blog which we update together regularly. It's great for him to look back on and stops a lot of repeated questions. So we really recommend this to parents, it's very quick and easy to do. It's also great for his teaching staff and therapists to look at because they can see what he does over the holidays and what he likes to do. The blog is called William's World - [www.willstouring.blogspot.co.uk](http://www.willstouring.blogspot.co.uk)



**William Newton**

**Age:** 6

William lives in Warwickshire. He was diagnosed at 3 years old with ASD and SPD (Sensory Processing Disorder - often part of autism). He attends a specialist mixed school, where he is very happy.

He loves anything to do with transport and maps. Using his iPad is the most important part of his day. He loves watching YouTube footage of people playing Minecraft and transport simulator games. Google Earth is also a favourite.

He has memorised the

**I love:**  
Maps  
**I hate:**  
Haircuts

## Cover Star

★ **Lucy Megan Darbo** ★

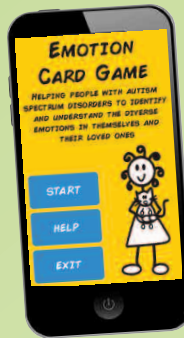
Age: 6



Lucy has autism and is from Manchester. She likes animals and enjoys days out at the zoo, park, shopping, swimming and spending time with her friends and family. She loves going to school and interacting with new people, she also likes eating. One of the few things Lucy dislikes is other people shouting. She lives on a busy road but likes it because the shops are only just across the street and she likes being treated!

## GIRL WITH CURLY HAIR GOES MOBILE!

The Curly Hair Project (aka author Alis Rowe) has released a mobile app, the Emotion Card Game, available on the Play Store for Android phones.



The app is designed to help people on the spectrum identify the diverse range of emotions in themselves and others.

You can play using either of two options, either emotions only or

emotions and situations. The Emotion Card Game is available for £1.99 in the UK and will be available worldwide. Visit [www.thegirlwiththecurlyhair.co.uk](http://www.thegirlwiththecurlyhair.co.uk) for more information about the curly hair project, and for screenshots and videos of the app.

The Emotion Card Game has been developed by Alis Rowe, a regular contributor to AuKids, and programmer Mark King, himself on the spectrum who contributed to our Tardis feature in Issue 24.

Tried it and liked it? Why not send a review (no more than 200 words) to Aukids magazine? The winning review will be published in our January 2015 issue and its author will receive an AuKids 'Autism Sundae Dessert' poster. Email your review to [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com) no later than December 5<sup>th</sup> 2014.

## Curtain up on Big Top App

**Circus Starr has launched a brand new, interactive visual story app to help children with autism access live performance. Its Show and Tell app is available free from the Apple store and can be used on an iPhone or iPad.**

Show and Tell provides a photographic feast of live action circus images, exclusive behind-the-scenes material as well as show footage that will help children familiarise themselves with the circus experience before they go.



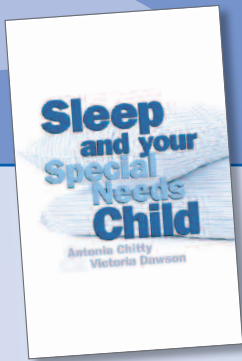
All content in the app can be personalised to suit the specific needs of each child and children can even put themselves into their stories by uploading their own images, footage and text.

The app's launch coincides with the start of Circus Starr's autumn tour.

Show and Tell has been developed by award-winning app developer, Therapy Box in association with the National Autistic Society. It is part of a wider research project supported by the Digital R&D Fund for the Arts investigating how digital technologies can be used to increase participation with the arts more broadly.

For more information on the autumn tour, go to [www.circus-starr.org.uk](http://www.circus-starr.org.uk) To access the app, go to [itunes.apple.com/gb/app/circus-starr-show-and-tell/id906662040?mt=8](https://itunes.apple.com/gb/app/circus-starr-show-and-tell/id906662040?mt=8)

# Reviews and Prizes



## BOOK

### Sleep and Your Special Needs Child

By Antonia Chitty and Victoria Dawson  
Published by Hale  
£12.99 • ISBN 9780719807916

This book is co-written by Victoria Dawson who founded the Children's Sleep Charity and Antonia Chitty who writes on health issues, and is written for parents of children with special needs. The book is divided into ten chapters, the first four of which discuss the importance of sleep, types of sleep difficulties, other sleep problems and daytime activity and sleep including the effect of medication and diet.

The next four chapters look at the importance of a bedtime routine and the bedroom environment as well as ways to change bedtime behaviour and to promote relaxation. The final two chapters are dedicated to specific additional needs, including autism and ADHD and the authors give some useful case examples of issues affecting different children, and how to plan your intervention.

Parents wanting to improve their child's sleep pattern will find this book very readable; it is presented in clear sections so parents who want to read about a specific topic can do so easily (this is also helped by a clear index) and the final chapter will help you to plan your approach.

Chris Hoyle  
ASC Sleep Clinic Coordinator



## BOOK

### How People With Autism Grieve, and How to Help: An Insider Handbook

By Deborah Lipsky  
Published by Jessica Kingsley  
£12.99 • ISBN 9781849059541

From the author of 'Managing Meltdowns' and 'Anxiety to Meltdowns' comes this insightful handbook on how people with autism process grief. Deborah Lipsky describes herself as having high functioning autism and has a background of working in emergency and trauma management.

Using both case studies and her

own personal experiences, Deborah explores how people with autism deal with difficult news and express grief in ways that are different to 'non autistics'. The book offers practical advice on telling an individual with autism about a death and on preparations and adjustments that can be put in place prior to funeral ceremonies.

Deborah advises setting up a plan for the death of a loved one and includes a template for both expected and unexpected deaths. Although covering a sensitive issue, the book is written in a way that is engaging and easy to read. Deborah articulates herself so clearly that her thought processes and actions following the death of a loved one become both understandable and logical.

The book is a useful for tool for professionals, family members and friends of individuals on the autistic spectrum.

Hanna Venton-Platz  
AuKids magazine readers' panel



## EVENT

### Autscape Conference

Belsay Bridge Conference Centre, Ditchingham, East Anglia  
August 4<sup>th</sup>-7<sup>th</sup> 2014 • [www.autscape.org](http://www.autscape.org)

**Amanda Haydock has autism and is a children's support worker at Time Specialist Support in Manchester. This year she attended Autscape, a conference in the UK run by people with autism and for autistic people. Non-autistic people are also welcome but the environment and content are centred on autistic people's needs.**

Imagine a world in which you are told your child has autism and instead of being given a list of what's 'wrong' with them, and how life will always be a struggle, and how they will never 'recover', and how it's unlikely they will be able to form and keep relationships... Imagine if, instead, you were told that yes, your child is neurologically atypical... and it will be hard and you will all learn many lessons along the way...but that it will be okay.

That's the biggest thing Autscape said to me this year – that it will All. Be. Okay.

In this miniature world where I had a typically atypical brain (that is, most other people there were also autistic), I didn't feel disabled. It was structured, calm, and egos and judgement were absent. As emotionally sensitive as I am, I easily met people who share the view that if anything, we are MORE emotionally connected to the world around us than non-autistic people are (I am generalising).

I had to laugh when, during a workshop that encouraged us to pathologise the neurotypical state, many people strongly opposed the idea. It seems they did not wish to make any neurotypical feel ashamed or disordered because the audience felt they did not have that right. When in fact, this is what non-autistic people do to autistic people all the time. Who has more empathy here?

Here at Autscape is a community of autistic adults who are being empowered by belonging to that community. It matters to me that this community is working to change perceptions of autism.

Autscape is a microcosm of what the larger autistic community could be; where views

are debated and friendships forged and people encouraged to be themselves in a world that is always trying to force conformity.

At Autscape people 'stim'. They talk if they want to and don't if they don't. They hug if they want to and don't if they don't. They are quiet in the corridors. They flap instead of clap. They look at the communication badges before they speak to someone. (Communication badges at Autscape give others a guide as to whether the person wants to be approached or not). Difference is accommodated without the scrutiny of WHY.

The autistic community at Autscape is every bit as loving and caring as any non-autistic community I have ever encountered, only perhaps more so. It makes me smile on the inside when I see a community no longer willing to take any kind of discrimination lying down. I smile when I think of a community that's ever-growing, willing to accept new members, that will welcome little autistic people and show them that they are not wrong. I smiled when I saw a little autistic boy lying under the chairs, scripting his little heart out with a huge smile on his face; being allowed to be himself.

And so I also smile when I see categorically that it will All. Be. Okay.

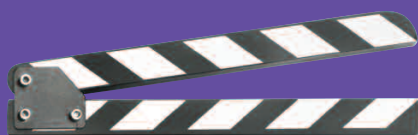


## Competition Time

**Win 3 sets of family tickets to the cinema with Cineworld!**

Those kind folks at Cineworld know that you'll be dying to treat your little ones to their autism friendly screening of the Christmas blockbuster.

We have three sets of four tickets to give away to a Cineworld screening of your choice at your local cinema. You may wish to take your family to the ASD-friendly screening but it's up to you how you choose to use them. There are 21 Cineworld cinemas currently taking part in Autism Friendly Film Screenings on the first Sunday of each month at 11am. You can find the closest Cineworld to you at [www.dimensions-uk.org/support-services/autism-care/autism-friendly-screenings](http://www.dimensions-uk.org/support-services/autism-care/autism-friendly-screenings)

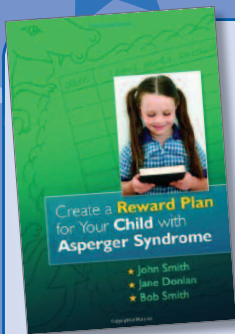


To win your tickets, simply answer the following question:

**What was the UK's highest grossing film in 2013 - Was it:**

- a) **Monsters University**
- b) **Despicable Me 2**
- or
- c) **Wreck It Ralph?**

Send your answer to [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com) no later than November 20<sup>th</sup>, stating 'Cineworld' in the subject header. Or you can post the answer to us at AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE. The first correct three answers selected out of our sparkly hat (we really do have one, honest) will receive free tickets for a family of four. Don't forget to include your name and full address. Good luck!



### BOOK

#### Create a Reward Plan for Your Child with Asperger Syndrome

By John Smith, Jane Donlan & Bob Smith  
Published by Jessica Kingsley  
£13.99  
ISBN 9781843106227

This is an engaging, very personal manual collaboratively written by Jane Donlan, John Smith and their son, Bob. They live in the North West of England and Bob, now 12, was diagnosed with Asperger's at the age of eight.

It is admirable that the parents had the courage to open up and speak about some of their struggles in a very personal way, such as Bob's tendency to experience emotional overload often leading to physical aggression towards his mother. From what I understand, this was the motivation behind this book; Bob's parents want other parents to feel less alone and have a reward strategy in place in order for them to cope.

Despite having some problems, the Donlan-Smith family are a very happy one and all of them, including Bob, are very loving people. They have reinforced the positive aspects of their relationship

and their ethos is to devise strategies for a mutually beneficial and happy future, not to just give up or avoid a problem.

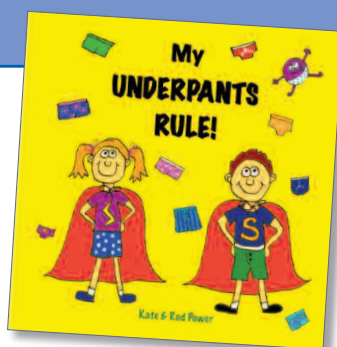
I liked the book's illustrations and imagine it would be extremely helpful for parents and teachers to see the stick figure drawings and thought bubbles, which encourage the reader to acknowledge and accept different viewpoints.

The reward plan is a means for the child to receive 'points' for positive behaviour, for example, doing something they find difficult, such as a particular social skill. I endorse the philosophy behind their plan, that reward points should never be taken away; children should be rewarded for their good work or efforts at the time, even if the next day is a more difficult one.

The book's base plan can be adapted over time with the aim of helping your child to develop positive behaviour and become more independent.

I must say I am a bit surprised by how much I enjoyed it! Like most ASD books, the dull green front cover did not initially excite me. But by the end of it, whether you're a parent or teacher, I am certain you will feel more confident and uplifted.

Alis Rowe (who has Asperger's)  
AKA The Girl with the Curly Hair



### BOOK

#### My Underpants Rule

By Kate Power  
Published by Kids Rule Publishing Ltd  
Available from Amazon.co.uk for £6.99  
ISBN 9780992953003

We don't normally review books that aren't aimed especially at autistic kids, but this one is so accessible and smart that we felt it worthy of a mention. My Underpants Rule, written by ex-police officer Kate and her husband Rod, is a colourful, simple, short and lively guide to staying safe from predators. The cartoons on every page make it easy to navigate and the book is totally in rhyme, so is highly memorable. I liked the simple questions at the end of each point, checking for understanding. This is perfect for any parent wanting to

broaden a delicate subject without being scary. Great job, Kate! A personalised version of the book is available for £7.99 from U Star Novels.

Kate says: "We've written My Underpants Rule! to help parents talk to their children from an early age about off-limits body parts, inappropriate behaviour and how to recognise if a relationship with an adult is not normal, ensuring these lessons stay with them for life."

Debby Elley  
co-editor

## WIN IT

We have three copies of My Underpants Rule! to give away. Simply answer the following question:

**Q What job did the author do before she wrote this book?**

Send your answer with your name and full address to [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com) before the closing date of November 30<sup>th</sup> 2014 quoting 'Underpants' in the subject header. You can also send your answer by post to AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE.

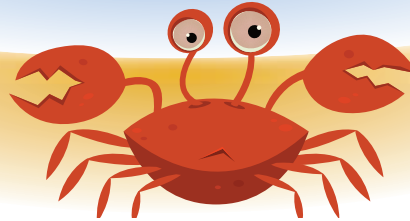
**Good luck!**



“ My pre-verbal son has always been quite docile but recently has started to pinch people. I’ve tried the usual parenting stuff but it doesn’t seem to work... ”



Is there a problem with my behaviour?



**Tori Houghton**

Highly Specialist Speech and Language Therapist in Autism.

Director of Time Specialist Support, a support agency for children and young people with autism. Oh and co-editor of AuKids.

First of all it's easy to think about any behaviour that we consider difficult or socially unacceptable as a negative thing. Sometimes behaviour can be viewed as a developmental step, a positive leap. With your son's pinching, it may be that he is beginning to realise his impact on the world and that he can have some control over his environment.

But that's not to say that this kind of behaviour should be encouraged. The most important thing is to look at the function of it and the reason behind it.

There are three main reasons why your son may be pinching and the way you respond really does depend on its function. The first thing to do is to closely observe his behaviour and see why you think he is doing it:

**1. Communication:** It could be that the pinching is your son communicating

something to you. He may want something, might be saying "no" to something, might need you to hurry up, move away etc. Again, it's important to observe it and try to work out what message he is trying to give you. If this is the case, then looking at reshaping this behaviour into a more appropriate form of communication – the introduction of pictures or symbols to help him express what he's trying to say, would be helpful. Always try and say the word or phrase that your child would use if he had the words.

**2. He likes your response:**

Perhaps your son likes the way you respond to his pinching. Children who may feel out of control in other areas of their life may exhibit behaviour which helps them feel back in control. Think about your response to his pinching. Do you always say "no" in the same way? Do you remove him somewhere and put him somewhere quiet? It may be that he finds it hard to differentiate between 'good' and 'bad' attention. If this is the case then the best advice would be to try and ignore the pinching and to not react to it.

**3. Sensory:** Perhaps your son enjoys the sensory experience that he gets from pinching. In this instance, try and think of more suitable objects or substances for him to pinch, such as Blu Tack™ or Play Doh™. An Occupational Therapist may be able to advise other activities that support this need.



**Deborah Plummer**

Author and storyteller, formerly clinical lead speech and language therapist and senior lecturer in health studies at Leicester De Montfort University

'Normal parenting stuff' may, in fact, be a good basis for responding to your child's needs in this situation, although much repetition may be needed in order to help them to regulate their own emotions and responses.

There are many reasons why non-verbal children might start to pinch or hit others. For example, your child may be indicating frustration and/or anxiety about not being able to communicate something effectively just at that moment; they may be feeling overwhelmed by a situation or perhaps they are seeking attention but don't yet know how to moderate their actions so as not to hurt others.

For some children, pinching or hitting results in a reaction that is exciting or enjoyable. Seeking that kind of reaction could also be an indication that their sensory system is under sensitised and they are trying to balance this out and regulate it by seeking more stimulation.

It is important to look for likely triggers in order to understand your child's motivation for pinching others. Whenever possible, try to respond to the underlying feeling or need rather than just to the pinching.

In the first instance, a swift response such as putting up your hand in a 'stop' sign and saying 'no thank you', then redirecting your child's attention with minimum fuss can be effective. Be firm but calm and try to get as many other people as possible to use the same response.

Is there a preceding tell-tale sign – perhaps a facial expression an 'approach' gesture, hand clasping or finger flexing that indicates the imminence of a pinch? Try to intercede at that point with an alternative. Offering something else that they can pinch, such as a soft foam ball, can be helpful.

Whatever your child's motivation behind the action, remember, pinching and hitting are a form of communication. Removing the opportunity for a child to communicate their feelings or needs in a particular way can simply cause more stress and anxiety unless they are shown an acceptable alternative.

If you believe that your child is expressing frustration, anxiety, the need for more stimulation, or indeed is expressing pleasure or excitement by pinching others then think about what you could encourage as an alternative. Demonstrate and encourage this alternative repeatedly and praise your child when they manage to moderate their actions.

So the key points to remember are:

- Respond lovingly and calmly
- Be consistent with your chosen response
- Tune in to the motivation behind your child's action
- Show that you have understood your child's intention, feeling or need.
- Demonstrate and reinforce an alternative way of expressing that intention, feeling or need.



**Heather MacKenzie**

Speech and Language Pathologist and Founder of the SPARK\* programme (Self Regulation Program of Awareness and Resilience in Kids)

The first thing that strikes me is that you describe your son as previously 'quite docile', suggesting that he reached out to others very little and initiated interactions infrequently. Therefore, the 'pinching' is actually a nice step toward acknowledging and, perhaps, trying to engage others.

Now for the down side of 'pinching'....

**Sensory integrative side:** So many of our children have no idea how intense their grasp is. Give him benefit of the doubt and help him develop a better feedback loop (body to brain and back) so touch and grasp can be in gradations. Start by practising with a soft ball.

Print the symbols for 'soft' and 'hard' and be sure to put the written words on the pictures. Practice 'soft' and 'hard' squeezing of the ball with your child, pairing each with the symbol and printed word, until he can demonstrate the differences and understand the words for each.

**Social knowledge side:** We also want to keep him reaching out for others but in more appropriate ways. A good first step is to determine exactly when he tends to 'pinch'. Does he do it if you're talking to others or not paying attention to him in some way? Does he do it when you ask him to do something he may not want to do? You'll have to try to figure that out. After you've narrowed down one or two typical situations when he tends to 'pinch', think of more appropriate ways he could communicate his thoughts or concerns. If he wants to gain your attention, you could set up visual support that indicates, when you want Mummy to talk to you, you can touch my arm with your 'soft' touch. ALWAYS present the new ways of responding in positive language, stating what your child can do. ALWAYS avoid telling your child not to do something (e.g. 'do not pinch'). That just tends to reinforce the whole idea of 'pinching', keeping it alive in his memory, and perhaps making it more exhilarating.



**Luke Beardon**

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

Children with autism really do like to communicate, in all sorts of diverse ways, and I suspect that this kind of contact – painful though it may be – is a form of communication! So, it all boils down to a couple of key things – what is it that the child is trying to communicate, and is there an alternative form that can be taught to transfer the 'pinch communication' to something that might be considered more appropriate or, at least, less painful! The latter may depend on the former; if the pinching conveys a range of different communications then you may need to develop a different range of communications as a result.

It may be worth trying to ascertain if there are any specific contexts in which the pinching occurs, which may subsequently help identify what is being communicated. The usual factors need to be considered – are there any triggers, consequences, particular settings and so on – the ABC (antecedents, behaviour (which we already know) and consequences) can be useful, or STAR (setting, triggers, action, response) charts can be used if need be.

PECS (Picture Exchange Communication System) can be a good form of communication for pre-verbal children, as it encourages spontaneity of communication (rather than prompt dependency). If the child is pinching as communication then developing PECS may alleviate the behaviour. What is important to note, is that if the child is pinching successfully – i.e. getting what they want as a result – then they may well learn that it is a very effective use of behaviour, and will therefore continue to use it!

Having said all of that, there are some other possibilities as reasons behind the pinching. The child may be trying to gain some control over the environment, they may enjoy the feel of pinching (from a sensory perspective), or they may like the reaction of others following a pinch!



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For more information on any of our services please visit [www.cygnethhealth.co.uk](http://www.cygnethhealth.co.uk) or call Cygnets Central: 0845 070 4170

For more information contact Saskia Little, Administrator  
Tel: 0161 443 4060 Email: [peterlawson@cygnethhealth.co.uk](mailto:peterlawson@cygnethhealth.co.uk)



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# We Are Sailing!

## CONVERSATION SERIES PART 2

In part one of our conversation series last issue, we talked about encouraging a pre-verbal child to recognise that they can get what they want through communicating – either using gestures and signals or verbally.

We used the analogy of rowing a boat to explain how children with autism can gradually learn what communication is for.

In the second part of our conversation series, we'll be rowing a bit faster.

Now we're using conversation not just to ask for something, but for a host of other reasons, too.

By Tori Houghton  
& Debby Elley



### Rowing Together

Does your child mostly hear conversation only when it's directing them? Are most of the exchanges that take place in your house a one-way street?

When a child doesn't start a conversation with you, it's difficult to get beyond the basics – but it can be done, trust us!

Let's get back in our imaginary boat and show you how.

### There's A Bridge Ahead!

Firstly, it's important to recognise that conversation can happen even without words.

In our boat, when your child dips their oar in the water and then you follow, building a pattern, you are rowing forward together. It doesn't matter how well it's done.

In real life, non-verbal kids (or pre-verbal as we like to call them, never say never...) *do* have conversations. Intensive interaction expert Phoebe Caldwell recognises certain hand movements as a form of conversation that's taking place – the child using their own body language to talk to themselves.

Follow the lead, copy the movement, and that becomes a conversation that involves you, too. If they glance up at you, you've cracked the code!

Most pre-verbal kids make noises, too, even if it's not recognisable speech. Copy that, build on the number of exchanges you get, and you're having a conversation. It doesn't matter if it's nonsense to you. They're involved in a two-way exchange and that's what counts.

Why do we do this? Because developing turn-taking – and recognising that someone else can be a part of your world – helps them to understand the purpose of language. And even if they never develop speech, then you will still have a non-verbal dialogue with them that carries meaning for both of you, enriches your relationship and reduces their sense of isolation.



### Taking in the Scenery

The next big deal in our boat is building vocabulary. Can this be done with someone who doesn't talk, or hardly talks? You betcha!

Announce items as you both work with them, using one word only so that the meaning is clear: soap, tap, toothbrush, flannel, bowl, spoon... This technique is called 'labelling' and it helps build **receptive** communication – that is, a child's understanding.

### Let Them Choose the Direction

One trap we often make when rowing in this boat of ours is to grab the oar, making our child go a bit faster!

Let the child row by themselves, choosing where they go.

Making choices encourages your child to develop an internal dialogue: 'What do I think about this?'

Think about the daily choices you make for them without even thinking. Which top to wear, what to put on first, what cereal to have... Choices are important for communication, self awareness and self esteem.

Recognise gestures, signs, symbols, pointing and any sort of vocalising – and ask for a choice.

### Row at the Same Pace

With a youngster who is just developing language, you want to row in the same direction as them and with a synchronised pace. There's no point in charging ahead if the little oarsman with you can't keep up.

So match them for pace, tone and the number of words they use. Our co-editor, speech and

language therapist Tori says: "When you match their pace correctly, it really works in terms of building communication. By slowing down to their pace it gives you an opportunity to reinforce the skills they already have at their own natural rate."

Praise and reward is really important; respond to subtle messages and copy what they're doing, which is another form of praising it. You may have to look quite closely for signals, but by slowing your own pace, you'll spot them.


### Getting More Out of That Oar!


Once they start getting confident rowing in a straight line from A to B (i.e. asking for something and getting it) you need to teach your little oarsman what else can be done using their 'oar' (communication).

This is what we call the functions of communication. Here are some **functions** recognised by speech and language therapists to be important for the beginner.

Each function is divided into two groups to show you how you can build conversation skills for a pre-verbal child (no clear words) and a verbal one (some clear words).

### Commenting

 **NO CLEAR WORDS:** When they watch something, **model** what they would say if they could. Respond to signals, sounds, expressions, gestures - or even eye gaze - as if they are actual comments. This shows them the function of a comment, building conversation by your response. E.g. "Wow! Noisy plane!"

 **VERBAL:** Use reflection to repeat what they've said to help them extend it in a non-threatening way.

e.g. "What did you do today?"  
"I played with Kevin."  
"Played with Kevin?"  
"I played Pokemon."  
"Played Pokemon with Kevin?"



# Terminology...

(...Which Will Make You Look Like You Know What You're Talking About)

## Language function

The huge range of purposes that we use language for. At the start of communication language is purely used to ask for something. It's only a lot later that it takes on a social function.

## Expressive communication

Language, whether it's verbal, signs or symbols.

## Receptive communication

Understanding of language – this often comes before expression, so it's important to build on it before you get any clear signals back.

## Mapping

This is speech therapist talk for 'labelling'. When you point to something and simply say the word for it, it's mapping. Autistic kids don't drink in words as naturally as neurotypical ones, so it's important that you 'map' a lot.

## Labelling

Are they looking at it? Tell them the word. Not just once, but every time it happens. Bore yourself with how many times you do it.

## Modelling

Another word for demonstrating. Pick up on what the child would say if they could, and demonstrate it. "No, I don't like that!" Say it from their viewpoint, not yours. Modelling, which is positive, is far more effective than correcting, which can cause a child to lose confidence and try less.

## Sabotage

Awful word for a powerful tool - AuKids calls it 'friendly sabotage'. If your child is in a regular routine, throwing a spanner in the works to disrupt it by pausing or not giving them exactly what they expect can create real motivation for them to put you right by responding. Try not putting a spoon with their cereal, for instance, or avoid sticking the DVD in the recorder until they find a way of telling you they want the DVD on (whacking you in the arm with the case is a good enough signal). Then model what they're trying to tell you: 'Ah - I want the Fireman Sam DVD!'

## Reflecting

Repeating the last thing your child said to you is a way of reinforcing their attempts at conversation. A lot of questions can seem quite demanding, but reflecting often encourages further information. Avoid temptation to follow up a comment with a series of questions. Good luck!

This **reflecting** is amazingly effective. It shows no judgement and requires nothing extra conjured 'out of the blue' but encourages your child to delve deeper with their or.

## Requesting

**NO CLEAR WORDS:** Even if your child has a regular routine (and what autistic child doesn't?) try not to guess the decision they're about to make. Show them that a request is an important function even if you feel you know the answer. Make it clear that you aren't prepared to guess what they want, but take the smallest signal as a firm request and praise it.

**verbal** **VERBAL:** Model the correct way of saying something e.g. 'Me want...'  
'Yes, I want...'

Verbal kids should be taught the difference between three types of question:

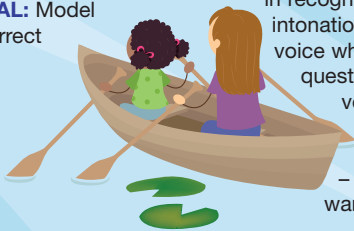
*Social: Does someone just want a quick answer to indicate you're ok and doing well?*

*Testing: A question asked at school, where the teacher already knows the answer.*

*Information gathering: Wanting to know more.*

The difference between these isn't obvious to a kid with autism.

Verbal children may have difficulty in recognising the change of intonation in someone's voice when they're asking a question. Use your own verbal punctuation to help flag up a question: "Darren - Question: Do you want some toast?"



## Refusing

**NO CLEAR WORDS:** When you know it's a 'no', show them a symbol or sign and **model** what they'd say - e.g. When they push something away, 'No - I don't want it.'

**verbal** **VERBAL:** Give them different ways of saying no, modelling polite ways of refusing something and explaining about people's feelings.

## Asking Questions

**NO CLEAR WORDS:** Tune in to their facial expression and if it is querying, model the question. Create a question through **friendly sabotage** e.g. hide something and then say: 'Where's it gone?!' with sign language.

**verbal** **VERBAL:** Verbal children with autism can have a habit of using questions as an excuse to tell people what they like. They may also use constant questions as a way of expressing worry. Spot the emotion behind the question before you interpret it as a genuine query. If it's not really a question, you can point it out: 'You have asked me that a lot of times. Do you mean that you're worried?'

## Expressing Feelings

**NO CLEAR WORDS:** **Map** expressions when you see them. Point out body language in yourself and others and explain what that person's feeling. Slow it down - show symbols when you recognise an emotion in them and **model** what they'd say: "I'm worried about this, mummy".

**verbal** **VERBAL:** Explain body language and play games to reinforce understanding. **Label** emotions whenever you see them and point out expressions on TV.

## Asking for Help

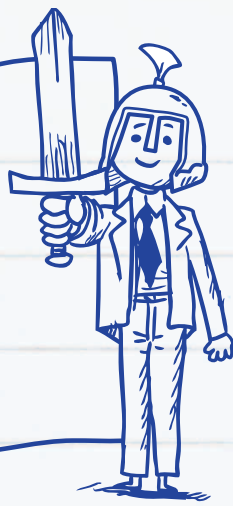
**NO CLEAR WORDS:** Get into a situation where you know they need help. Then show them a sign, gesture or symbol. Give them the word at the same time. **Friendly sabotage** can help.

**verbal** **VERBAL:** Anxious drivel is sometimes a way of asking for help. Point it out. "You seem a bit worried. Are you asking me for some help?" Help them to learn how to turn negative behaviour into a request.



WATCH OUT FOR PART 3 IN OUR NEXT ISSUE!

# GLADIATORS of the CLASSROOM



They champion your child's needs, keep them on track with endless small persuasion tactics and strive for inclusion, often with little support of their own. Yes, it's that brave, fearless, resourceful breed - the Teaching Assistant (T.A.).

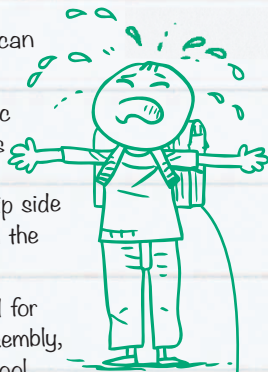
Starting this term, Education Health and Care Plans (EHC) are gradually being rolled out to replace Statements. One of the purposes behind the new system is to encourage schools to 'up their game' and gain extra expertise within, so that teaching is adequately tailored towards the learning styles of kids with autism.

So, we asked a group of experienced T.A.s for their best advice on supporting autistic kids in mainstream settings.

TOP TIP: For a fab guide on how the system is changing, go to [www.skybadger.co.uk](http://www.skybadger.co.uk)

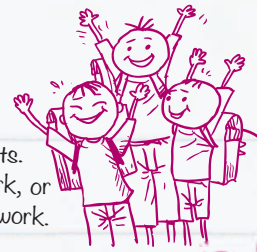
## DIFFICULT DAYS

- Don't try to squeeze a good day's worth of work into a bad day. You can often make up for it on good days.
- Don't worry if you have an 'autistic day' when a young child just wants their own company. Accept that their productivity fluctuates. The flip side is that on productive days, kids on the spectrum can move mountains!
- If they don't want to get changed for PE, or appear on the stage in assembly, is it really going to harm their school career? Focus on the things that really count.
- Have a quiet place for retreating to, with no pupil traffic through it.
- If the child tends to run when they're upset, make sure they sit near to the front of the classroom so that the assistant doesn't have to run through an obstacle course to follow them. Be especially careful of stairs, as 'runners' can rush down them without care.
- Parents: pack fruit and a drink in your child's bag, they can be a good comfort and energy boost after a meltdown.



## MOTIVATION

- Give the child time to indulge their special interests. Use it either as part of work, or as a reward to encourage work.
- Timetable ten-minute breaks on the computer to avoid it being the focus of the day. The child will be a lot calmer knowing exactly when they can have their computer time. Use 'plus' minutes on the computer as a reward and 'take away' minutes if they're playing up.
- If a young child is getting too attached to computers, put a blanket over it and say that the computer is having a 'rest time'.
- If they are finding something entertaining enough to be echolalic about it (repeating it often), use it as handwriting practice.
- Special interests (e.g. Mario or Minecraft) can become part of stories - think outside of the box when it comes to the National Curriculum. Autistic children find it hard to file new information; by hooking it onto a special interest it becomes easily accessible.
- Don't expect an autistic child to be interested in the same rewards that you give to other kids - a sticker for being good, for instance, won't have the same effect because social acceptance isn't at the top of their list! Have something that they like to hand so that they are reinforced in the same way as the others.

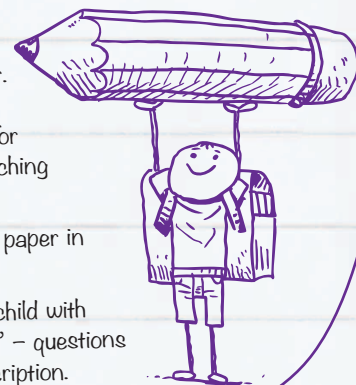


## WORKING TOGETHER

- Make time to find out what's going on at school. Talk to your child's T.A. at the beginning and end of every school day. If they aren't available, talk to them about making sure that they are, so that you can support them better in their role and exchange information, support and advice.
- The home-school diary is an essential tool for building a good relationship with your T.A. Write in it daily if you can - just a short note to acknowledge that you've read what was written the day before if nothing else.
- If you know something has happened that will put the child in a difficult mood for the morning, be honest about it from the start. If you don't want to mention it in front of the child, just tell the T.A. that there's a note for them to read in the home-school diary.
- Tell your T.A. they're doing a good job! They're only human and encouragement from parents can make difficult times seem far easier.

## WRITING

- If ideas are fast but writing is slow, give a little leeway and allow for some typing on the computer. It needn't be every time, but the co-ordination of ideas and handwriting is sometimes very difficult for autistic kids. Or let them dictate ideas to their teaching assistant.
- Write blackboard instructions down on a piece of paper in front of the child.
- Imaginary stories can be nearly impossible for a child with autism to create. Instead create story 'scaffolding' - questions that a child can answer which will build up a description. Again, not to worry if the story focuses on special interests.



## SOCIAL SKILLS



- To encourage social interaction, get the children to read to each other rather than just to a teacher.
- If you're taking the child to do an errand around the school, take another little friend so that it's not always just the two of you. This will encourage a circle of friends.
- Rather than sit a child in isolation at a workstation, sit them with one other child who works quietly and isn't disruptive. Do this with different children. In one classroom we heard about, sitting at the workstation became a treat with a waiting list of candidates!
- If assembly is difficult, build attendance time up slowly – from 5 minutes upwards. Bring in fidget toys and a symbol to let them know it's time to be quiet. We find the Five Point Scale\* works well in order to help children understand the current volume of their voice and the level that's appropriate in certain situations.
- If they can't sit still at carpet time, let them use a chair at a nearby table or cushion and put something in front of them. Where and how they sit is less important than the fact that they are taking part.
- Social Stories™ are very helpful to explain what's expected at school at circle time and in reading groups. Reinforce them until the child is confident that they know what's expected.
- Adopt a buddy scheme for the playground to avoid isolation.
- Use sand timers to encourage turn taking.
- Young friends and other teachers can sometimes assume that social immaturity means a child with autism isn't very clever. Make sure you praise a child with autism for their achievements in front of other people.

"Tell me and I forget. Teach me and I remember. Involve me and I learn." -- Benjamin Franklin

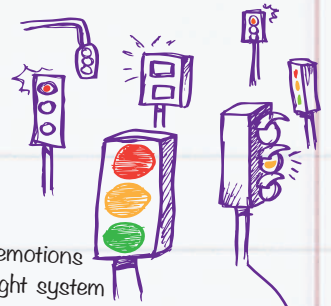
## CHANGE OF ROUTINE



- Visual timetables are really helpful. Even if a child seems settled, it's wise to adopt one at the start of every school year. The abstract nature of time can make focusing on pieces of work quite difficult. Countdown clocks and light-up traffic lights can be great for this too.
- Prepare an autistic child before the start of a new school year by letting them see the new classroom and writing down what they can expect.
- Give ample warnings of unexpected changes to the day – even fire alarms that should technically be a surprise.
- Prepare autistic children for a school trip with a picture story showing the school coach, the timetable for the day and a photograph of where they will be going to. Include what happens at lunchtime. Virtual online tours of new places are great preparation, too.

"Everybody is a genius. But if you judge a fish by its ability to climb a tree it will live its whole life believing that it is stupid." -- Anonymous

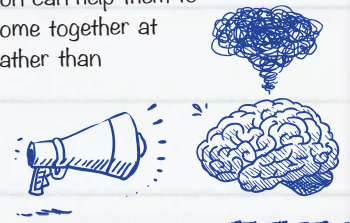
## MANAGING EMOTIONS



- Don't over-face an autistic child with a list of jobs. Just let them know what they're working on now and next, plus the reward.
- The Five Point Scale\* is a very useful book to use to help children identify how 'big' their emotions are getting, but you can equally use a traffic light system to help children to identify when they are starting to feel stressed.
- If the child's embarrassed to ask for help, have a card system in place. They can put a red card in front of them if they need help. A green card means they're ok working on their own.
- Dr Heather MacKenzie suggests putting a green sticker at the top of the area you want them to write/draw in and a red sticker where you'd like them to finish. Autistic children find the uncertainty of how much space to fill very daunting.
- Autistic kids can be like sponges and soak up emotions from others. Teachers should warn T.A.s when they're about to raise their voice to the class so that an autistic child can be taken somewhere else.
- Sometimes it's easy to know what it means to do something perfectly, but 'good enough' is hard to define. Struggling to be perfect, a child can melt down when they feel that they've failed. Specify what it is that they're expected to achieve for a task and reassure that perfect is isn't always possible and often isn't required.

## SENSORY DIFFICULTIES

- Use ear defenders during noisy times to prevent sensory overload. Keep them within grabbing distance in case of unexpected noise. Just knowing they're to hand can reduce anxiety.
- On a big table, autistic kids can find it hard to filter out the noise from classmates. A separate work station can help them to focus on written work, then they can come together at group work times where collaboration rather than concentration is needed.
- Arrange for the child to go into the dining room ahead of the others. A slow build-up of noise and crowds is a lot easier than walking into a room teeming with people.



## USEFUL INFO

Tools: Desktop visual timetables, Time Trackers, I Need Help signs, Portable Workstations and a load of other great stuff is available from [www.specialdirect.com](http://www.specialdirect.com) We really like the 'How's it going?' communicator for £3.00 - a colour-coded pyramid that the child can use to indicate whether or not they need help.

Guidelines for working with children with autistic spectrum disorders at Foundation Stage and Key Stage 1 by South Gloucestershire Council - published by the NAS

My Social Stories Book by Carol Gray and Abbie Leigh White - Published By Jessica Kingsley

\*The Incredible 5-Point Scale by Kari Dunn Barton and Mitzi Curtis - published by the National Autistic Society

# Living With the Little People

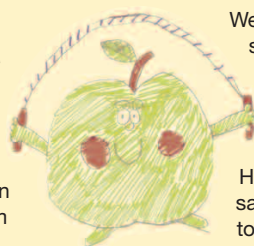


If we said it might be a good thing to have voices inside your head, you'd be forgiven for thinking we'd gone a bit nuts. But recently AuKids discovered a new approach that helps our kids to discover their hidden resources by doing just that. Creating their own army of 'little people' who live in their heads can help autistic kids to approach stressful situations with confidence and clarity. Here, authors of *The Homunculi Approach to Social and Emotional Wellbeing*, Anne Greig and Tommy MacKay, explain how the method works.



Dr Anne Greig is a psychologist for Argyll and Bute Council, Scotland and a practice tutor on the MSc Educational Psychology course at Strathclyde University. She has many years' experience as a teacher, researcher, applied psychologist and psychotherapist, specialising in mental health and the autism spectrum.

The Homunculi (Latin for 'little people') is a fun, cognitive behavioural therapy (CBT) based activity that builds social and emotional resilience in children aged seven up to teenage years. We developed the approach for kids on the autism spectrum who were hard to engage with standard interventions. Simply put, there was a glaring gap in helpful interventions regarding what to do with our youngsters once they had been diagnosed.



The story of the Homunculi began in our attempts to work with a newly diagnosed boy, 13 year-old Ian. He was struggling to come to terms with his diagnosis and got into trouble at school, so he stayed at home with his hoodie up.

After an initial difficult home visit, all we knew about Ian was that he liked computers and cartoons. During a coffee break later that day, Anne recalled a cartoon she'd enjoyed in her childhood called 'The Numskulls'. It was a regular comic strip in *The Beano* about some little guys who lived inside a boy's head and had an effect on the things he did, said, thought and felt. Basically, they were in charge of him, for better or worse!

The Numskulls also had cool gadgets like dream machines and snoring machines and lived in their own area of the brain: the ear department, mouth department and so on.

As we reminisced about this, Tommy happened to have a copy of *The Beano* in his briefcase (strange but true!) and he recalled a 'Speedy Gonzalez'-style character he'd invented for



himself who lived in his brain and helped him get through his work when he had too much going on.

We also chatted about the successful work of an educational psychology colleague, Laura Anne Currie, who created an imaginary 'Mr Homunculus' character. He sat on children's shoulders to help improve their literacy skills.

What if kids were able to create their own 'little guys' who would have special jobs, tools and powers to help them with everyday problems, we thought?

Cartoons and slapstick were known to be popular among kids with autism. Added to this we considered evidence dating back ten years that suggested kids with autism benefit from scripted, Social Stories as well as visual approaches, the use of technology and rules and routines.

Putting all this together, the concept of *The Homunculi* was born.

We thought this approach could be used with children like Ian, not only to engage them, but also to provide them with a virtual executive function - what we psychologists call a metacognitive, or 'thinking about thinking' approach.

The executive function is located in the front of the brain and its purpose is a bit like a pilot flying a plane or captain navigating a ship. That is, it is needed for monitoring, manoeuvring, focus, concentration, impulse control, planning, memory, organisation - all things known to be challenging

for those with AS-type difficulties.

In this approach, children invent their own characters and their own gadgets. We added certain rules for our programme, so that each cartoon would have a happy ending and a script. Impulse control features were built in for *The Homunculi* to use. We added thoughts and feelings devices inside the brain that the Homunculi could call on for emotion awareness training.

We then took the ideas back to our teenager, Ian. He loved it. He had very definite ideas about what was hard for him: talking to people, making and keeping

friends, nervous twitches, extreme emotions and wanting to sleep all the time.



He came up with his own ingenious characters to help him work out all the stuff that was hard for him. Our work with Ian is described in detail in our book and inside the book you'll find a link to the publisher's website where you can view footage of the characters he created, what he called them and why - and how they helped him.

Ian's cartoon became our prototype. At that time he was angry with his diagnosis and trying to come to terms with it. In later stories, he began to explore all the benefits of having Asperger's Syndrome.

We appreciated that some children would only want to make characters and talk about them, while others would want to do role play with them around specific problem situations. Some would enjoy making films, others would want to draw cartoons. The IT whizzes could download characters from the internet and use iPad technology.

Whatever their involvement, even the simple process of talking about characters, creating magical tools and taking conversation turns is potentially beneficial.

Our programme comes as a book that's designed to work as a kit. It's a flexible activity pack which includes a full guide on how to get started in creating your own Homunculi and missions to accompany them.

It includes photocopyable worksheets and a large poster-sized drawing of 'skull' – the head where the created characters will live and help the child to solve problems.

jungle, and their special agents were wild animals who had gadgets to help combat stress.

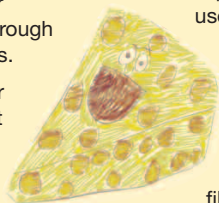


**WILD THINGS:** This group of kids used a jungle as a metaphor for the brain

For other children, their special agents were linked to different sorts of environments. They've compared their brains to prehistoric places, inhabited by dinosaurs; a food store with food characters; a football team with manager, coach and players; a pirate ship in angry stormy seas; the dressing room of a pop group and Planet Pokemon.

The metaphors and gadgets are all created by the young participant. However, they will need guidance. You will already know what their issues are by asking or observing them and through discussions with others.

For example, a teacher may have told you that there are violent outbursts but only during maths or on the football pitch. As well as finding out what others know and can do to help the school and community be more autism friendly, you then have the knowledge to kick start the



creation of the metaphor and characters.

We're developing this approach all the time and are currently looking into the creation of a Homunculi iPad App in which youngsters can use a menu of puppet and tool metaphors and background locations inside and outside the head. This has the added advantage of being a one-stop shop with built in filming potential, puppet drag technology where puppets can move and talk (you can even take a picture and add it to your own face), whilst being recorded at the same time.

A study we presented to the British Psychological Society in January showed the effects of working with The Homunculi. Mental wellbeing amongst kids who completed a ten-week course of therapy had significantly improved and they experienced reduced levels of anxiety, anger and stress.

How do you start your own programme? To begin, The Numskulls still appear in The Beano. Find a copy and read it together. Talk about what is hard at school or home and then ask your child: What if we all had these little guys helping us in our brains –

what would theirs be like and what would they do to help? And if you dare, you can even tell them about your own!

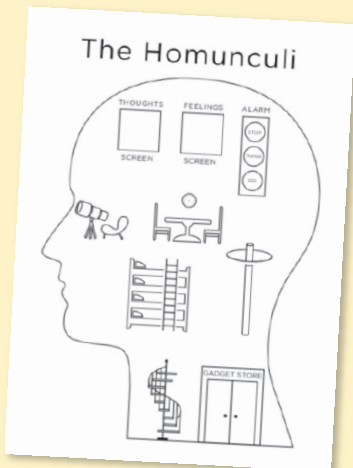
The trick is to make it great fun and to congratulate them for their fantastic ideas. Good luck!

### Here's One We Did Earlier...

The co-editors at AuKids loved this idea and we have invented our own Homunculi to help us with our problems! Debby's is Mr Bomb Diffuser. "Even if it seems I'm calm, inside I can get angry quite quickly. This character makes me wait whilst he works calmly to diffuse the anger bomb. Then he freezes it with a special ice shooter. I am hoping Bobby will borrow him one day!" Tori's homunculus is The Juggler. She often feels as if she's juggling and it's hard to keep everything in the air. "I worry I'll drop something and forget about a task. When I feel as if I've got too much to do, The Juggler will juggle everything for me and pass me only the most important tasks one at a time".



**What's yours?** If your child invents a little person as a result of this feature, please share it with us! Send their ideas to [auidsmag@gmail.com](mailto:auidsmag@gmail.com)



**MIND MAP:** The skull poster shows the tools that the Homunculi can use

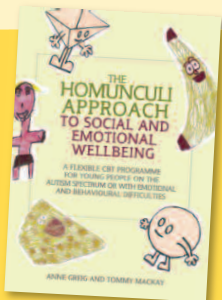
One of the most fascinating things in developing this programme was seeing how much insight our participants had into their challenges. They were also remarkably creative with characters and gadgets. Of course it is always good practice to start with what interests the participants and to begin where they are at.

A group of teenage boys on the autism spectrum were worried about their approaching exams. They compared the brain to a

## WIN the book!

Anne Greig and Tommy Mackay's *The Homunculi Approach to Social and Emotional Wellbeing: A Flexible CBT Programme for Young People on the Autism Spectrum or with Emotional and Behavioural Difficulties* is a book that comes with a free giant skull poster to get you started. The book contains links to associated footage that you can watch. We have **three** copies to give away! Simply send your name and address to [auidsmag@gmail.com](mailto:auidsmag@gmail.com) with 'Homunculi' in the subject header.

Prize winners will be selected at random from entries in by the closing date of November 30<sup>th</sup> 2014.



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# Clueless Comments

Your nerves are stretched, your patience thin, you're having the morning from hell and then some NOSY stranger decides that since life couldn't get any better, they'll pitch in with their own two penny's worth. Where's David Mitchell or some other master of the pithy put down when you need them?

Oh dear it must be so hard for you



It can be, but it's good to know I've got you to help me remember how bad things are when I'm actually feeling okay

UK with it, it's less than 1 in 100. That's why it's important that people understand it better.

My friend's child has that thing that's similar to autism, but he's quite normal.

**Tempting answer:** I think you mean Asperger's and you mean he's better at acting.

**Best answer:** You mean Asperger Syndrome? Autism is a really huge spectrum and people who never struggled with speech but still have difficulty with social skills and flexibility of thought used to be diagnosed with Asperger's. Now it's diagnosed as part of the autism spectrum. Some people with autism are really good at covering up their worries so that they appear 'normal' to you and I, but it takes a lot out of them to try and fit in.

Wow, so he's pretty clever then?

**Tempting answer:** He's not the thick one here, I think you'll find.

**Best answer:** Yep, he's clever alright! Autism isn't a learning disability. He may be a little behind with social skills but there's nothing wrong with him academically.

He looks so normal!

**Tempting answer:** So do you. You'd never know you were diagnosed with Thick and Tactless Syndrome.

**Best answer:** The way his brain works is very different to other kids. This is what makes it really difficult as a parent, because people can't always understand what they see.

Hopefully they'll cure it one day.

**Tempting answer:** You mean Thick and Tactless Syndrome? Probably not.

**Best answer:** Well I hope not, because some of the world's greatest scientists and inventors have been autistic. I don't want the autism removed because it's part of his personality. I'd like the stress and anxiety he experiences to be removed, but that's often down to other people. When people understand autism, it takes away the obstacles.

Awww isn't it sad though?

**Tempting answer:** I see you've come to brighten up my morning again with your energy-sapping pity.

**Best answer:** No, I don't see it as sad actually. I can see it might look that way to you because you're thinking of a normal child with something missing perhaps? Whereas to me, there's nothing missing, it's just a different way of 'being'. You do grieve at first but then you shift your focus and you start to see the world through their eyes and actually it's tremendously rewarding.

I couldn't do that

**Tempting answer:** You could and you would. Is this a compliment or an insult by the way?

**Best answer:** Thanks I take that as a huge compliment. It's just parenting the same as you do, but I use a slightly different toolkit, that's all! I'm not saying it's easy but when she does things that other people take for granted it is the most amazing feeling.

A bit of advice before we start with some choice responses... Choose to armour yourself by responding to comments positively. This means adopting the politician's tactic of answering the question that you want to answer, not the one that was asked. You do this in a tone that suggests the question was perfectly understandable, not a load of rubbish asked in a tone you didn't much like.

In responding to clueless comments, your first move is to quickly identify the intention behind the intervention. Is it:

- a) Attempting to be understanding?
- b) Rude and judgemental?
- c) Threatened?
- d) Just staring in your direction? (This isn't a comment but parents often feel as if it is).

Then react accordingly. Below we've got a few examples of the sort of thing you might say, coupled with the things that you would like to say but wouldn't be strictly appropriate. We did that bit just for fun.

## CATEGORY A : Attempting to be understanding?

Your response should be geared towards educating the person, as there is some hope here. Think of the positive aspects of what they're trying to say. Don't be too harsh, even in the face of overwhelming ignorance.

Here are some more specific responses:

It's so good for my child having your child in the class.

**Tempting answer:** You're right, I guess autistic kids were put on the planet purely for the purpose of educating neurotypical kids on tolerance.

**Best answer:** Yes, he's taught me a lot too. I'm sure they'll learn loads from each other.

Wow I really admire people like you for how you cope.

**Tempting answer:** Like we have a choice.

**Best answer:** Thank you, but he's my son so I could never see it as coping, it's just alternative parenting techniques! Once you see life from his viewpoint, it really becomes a lot easier. It can be hard sometimes but it's him you ought to admire, as he has to put up with a world that's not really geared towards the way his brain works.

My neighbour's cousin's sister-in-law has autism.

**Tempting answer:** You mean there's more than one person with it?

**Best answer:** Everyone knows someone with autism, it's much more common than you think, there's about 700,000 people in the

He's nearly normal though!



Oh he's far better than normal



**He'll grow out of it.**

**Tempting answer:** Duhhhhh!

**Best answer:** No, he won't. Autism is a life-long condition, it's not something that just affects children. You're right though that people often get better at handling their condition as they get older. Maybe that's why some people think they grow out of it, but they don't.

**Are they good with numbers?**

**Tempting answer:** So you've watched Rain Man.

**Best answer:** That's a bit of a myth. It's true that lots of people with autism find numbers easy to deal with. That's because they struggle with abstracts and numbers are nice and concrete – they never move, they stay the same. But it's not true that everyone with autism is great with numbers, it's just that you tend to hear about the really gifted ones.

**Aren't they the ones with a photographic memory?**

**Tempting answer:** So you've watched Rain Man.

**Best answer:** Some people with autism have good memories, but not all. There's a lot more to autism than that.

**CATEGORY B: Rude and Judgemental comments**

Here, you need to be a bit more assertive and help the person to question their own assumptions and what little information they're based on. Bear in mind though that rude people who make snap judgements can be hard to educate.

A word to the wise – never, we repeat NEVER take anything said by Category B people to heart. To make a cruel comment based on a superficial glance says everything about them and nothing about you. Would they still have said that if they knew EVERYTHING about your situation? The answer of course is no.

We've heard stories of parents being close to tears because of the comments of others. You have so much bigger fish to fry than one passer-by whose intolerance is doing nothing for their blood pressure. It's not your job to get one over on people like this. Put them right, move on.

Here are some more specific suggestions:

**Can't you tell him to be quiet?**

**Tempting answer:** We couldn't print this.

**Best answer:** His noise is a result of his distress. I need to remove the source of his distress before the noise stops. Part of the reason his distress continues is that he's picked up on my stress. My stress is caused by your impatience at my child's behaviour. It'd be more helpful if you could give us some distance.



**Can't you control your child?**

**Tempting answer:** We couldn't print this

**Best answer:** What you're looking at isn't bad behaviour, it's distressed behaviour caused by his environment, because he has autism. What really helps is when people like you are understanding and offer to help.

**CATEGORY C: Threatened reactions**

These are comments made by a stranger who intervenes because your child has shown inappropriate behaviour that impacts on them in some way – grabbed them or their child perhaps. Educating the person is important. Again, this is unfortunate but it's not as if it never happens with neurotypical kids, so don't beat yourself up too much. (Debby fondly remembers the time that Bobby chomped on a boy's arm in a soft play area because he wouldn't get out of the way fast

enough. Spent a small amount of time bribing the injured party to keep quiet).

**Your child just hit mine!**

**Tempting answer:** He probably deserved it.

**Best answer:** I'm really sorry. He has autism. We do teach him not to, it just takes longer than it would with another child. Sometimes his emotions get too big for him to handle. He didn't mean to hurt anyone, he just didn't understand the rules. Thanks for being so understanding, though. I will take him away for a bit so that he can calm down.

(Do not whatever you do chastise your child in a different way to usual just for the benefit of those watching. If this really is lack of understanding then punishing won't help, simple signs and symbols will).

**Oi! Don't do that!**

**Tempting answer:** <<Thump>>

**Best answer:** Please don't take it upon yourself to tell my child off. She has autism and doesn't understand the usual social rules. I can assure you that she won't have meant to be nasty, she just finds it really hard to control her impulses. I will explain to her in a way she can understand.

**CATEGORY D: Just staring**

For those who stare, no words are required. Don't get too sensitive. It's natural for people to be alerted to noises that are loud or different (it's hot-wired in as a response to danger, we can't help it). That doesn't mean they are judging you negatively. There's no need to announce to the world that your child is autistic. You owe no one a justification.

Here's a thought to round it all off. Did you snigger at the 'tempted' responses? They took us a lot less effort to write than the considered ones. That's because the considered answers required us to manhandle our immediate impulses and put them in a box. A child with autism struggles with communication at the best of times. When under extra stress in a new environment, is it any wonder that they find it hard to control those impulses and opt instead for the easiest route?

We all would given half a chance! Finally, if you're reading this out of interest and aren't a parent of a child with autism, don't go thinking that there's nothing you can say without treading on our delicate sensitivities. Parents can always spot genuine empathy, even if clumsily phrased – and we can tell it apart from indifference, negativity and scorn. Sometimes, it's not what you say it's the way that you say it.

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# The Last Word

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

## Don't Just Look Up, Look Back

If you look up 'auto' in the dictionary, the first description is 'self'. The Collins dictionary I have on my desk, published in 1986, has the rather outdated, simplified (and in the case of the word 'children' plain inaccurate) definition of autism as 'abnormal self-absorption, usually affecting children, characterized by lack of response to people and limited ability to communicate'.

No matter how sophisticated our understanding of autism becomes as our kids grow, it's perhaps as well to remember that the 'auto' bit is forever at the heart of autism.

Bobby is 11 in December and it sometimes baffles me that there are people around him who still find his self-absorption disturbing. Because he presents them with small windows of opportunity in which they can engage fully with him, it perhaps gives the impression that the self-absorption is something he can be shaken from, if only they try a bit harder with him.

Bobby's mind is constantly busy. He gives animated commentaries recalling books or TV programmes word for word, re-living parts of Minecraft dialogue or scenes from Luigi's Mansion 2. An audience is unnecessary. He evidently enjoys his echolalia, it doesn't lock him behind bars or disturb him, however strange it may seem to some.

When he was younger, the only let up in this constant stream of consciousness was to ask us questions relating to it, mostly as an excuse to repeat something else that was familiar and comforting. You either entered into this on his terms (we did) or tried in vain to switch the topic onto something less alien.

As he's got older, Bobby's conversation skills have grown and grown. Whilst his conversation with

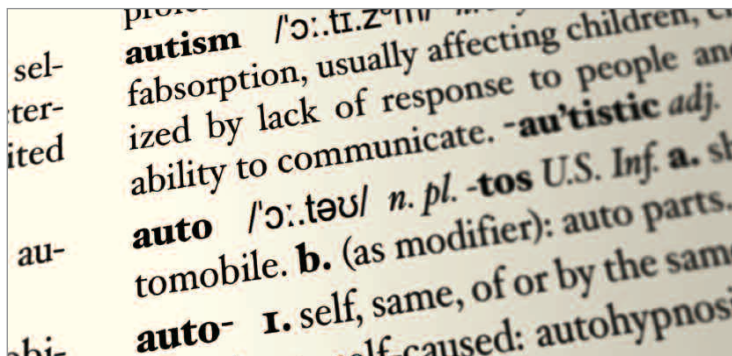
himself is always at the heart of it, new branches have sprung from which alternative buds of conversation have bloomed.

I've never stopped the party in my heart that happened when Bobby started to let us into his world. When we watched TV together the other night and he suddenly said: 'You know, Alec's brain isn't broken, it's just that he's forgotten language. The messages are getting scrambled,' you could have knocked me down with a feather. I have no idea where he gets his insight from.

When you hear neurotypical kids of Bobby's age chatting together in ways that he finds hard, it's easy to forget that Bobby's verbal journey has been an odyssey of immense proportions. Over seven years, his self-expression has changed from no eye contact and purposeful squeaks at the age of three, to tiny sentences at five, lots of words but not really full engagement up until the age of seven and then suddenly a massive spurt within the last three years, incorporating a leap in his ability to express his own emotions and to recognise emotion in others. If you want a 'normal' conversation with Bobby, you can have one, you just have to choose your moment.

So when people express frustration at his 'auto' bit, I feel like asking them how they'd feel if someone said that part of their personality meant they were lacking. How about considering the height of the mountain already climbed by someone who was born without the footholds, stirrups, ropes and harnesses that we all take for granted?

If pushing for even more engagement socially would mean that he wasn't autistic at all, then don't you think that perhaps he's climbed far enough?



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