

PARENTING AUTISM & ASPERGERS NEWSLETTER
VOLUME 5
MARCH 2006

Hi [[name]],

This is Dave Angel and I just wanted to say a big thank you to all of you who gave us your opinion in our recent survey on Aspergers.

Over 250 people took the time to tell us what information resources would be most valuable for them and their Aspergers Child.

If anyone else wants to take part and get a free copy of the original transcript to an interview I carried out last year with an expert Speech-Language Pathologist from Florida, USA on the subject of Aspergers Children - it's still open.

Just visit:

<http://www.parentingaspergers.com/Question.html>

So the upshot is that John Hillage is currently working away on producing some great new information resources as we speak.

Which means that I am taking over the newsletter again but don't worry as the layout and approach will stay the same; because it's based on what readers like you are telling us you want.

Well with that bit of "house keeping" out of the way let's get on with the newsletter so Welcome to the fifth edition of

"The Parenting Autism & Aspergers Newsletter"

Inside this edition you will find:

1. Hot Topic of Discussion – Labelling children.
2. In the News – Improving the classroom environment for kids on the autistic spectrum.
3. Parenting Tips - Humming in the car.
4. Famous Autistic Person - Jason McElwain: Basketball hero
5. Transporters DVD - Update Part 3.

Best Wishes

John Hillage

Labelling children

Earlier this month The Washington Post ran an interesting article about the trend towards, and effects, of the increasing labelling of children with autism, Aspergers and other such things.

It argued that in the past parents were more likely to fight against and deny such potentially stigmatizing labels.

But now this has reversed so that parents are actively seeking such diagnoses.

In the USA this is seen as being linked to getting their children extra time on tests, to receive insurance reimbursement for treatment, to qualify for extra educational services or simply to have a name (and treatment) for a problem.

Although this is clearly not the case for all parents and children as Stanford University psychology professor Carol Dweck cautions, "I think some children would rather be seen as 'odd' or 'quirky' than 'broken,' " others recognize how helpful the labels have been.

It is really important though to be aware of the impact that labels and stereotypes can have on people.

Labelling theory is something that has been studied in psychology for many years.

With the basic thoughts and a lot of research (such as Erving Goffman's classic work on "mental health asylums" in the 1960's) indicating that if you give people a label (such as "mad" or "dangerous") then sooner or later they will start behaving in that way.

It is felt that people will "live up" or "live down" to whatever labels are put upon them.

Now obviously a label is certainly not the only influence on how a person views themselves and behaves; but it can be a significant factor.

The article points out more recent studies into this area:

"Research finds that even subtle cues about stereotypes and associated expectations can have significant effects: Some studies have shown that simply being asked to check off 'female' at the top of a math test can lower the way a woman performs on a test.

Interestingly, if the woman happens to be Asian and is asked to identify her ethnicity rather than her sex before taking the test, her scores rise in line with positive stereotypes about Asians and math."

Carol Dweck then goes on to point out that it can be very useful for both the child and parent to have a label that will give them more understanding and scope to get the appropriate support.

But the key point that she says is "it's incumbent on parents to explain that 'Well, you may be wired a little differently; this might make it more difficult for you; you might have to work harder and use different strategies,' as opposed to 'This means you can't learn.' "

And for me that's the correct standpoint.

For so many parents in can be like fishing in the dark trying to do the best for their child if they know that "something is not quite right" but have no definite idea.

So a diagnosis of Aspergers for example can begin to clarify certain behaviors, give a better understanding for how the child's mind works and gives access to appropriate techniques to help the child at school, at home and in society.

But the downside can be that Aspergers then becomes an easy-to-blame excuse for no longer trying (for both the parent and child).

This kind of a "well he's got Aspergers we cannot really expect too much mindset" is what can be the real danger.

With low or no expectations this is always going to be a problem for the child and their family.

I am a big believer in the huge potential of all people with the right support and encouragement, and later in the article a psychiatrist Bruce Perry points out that "the brain is like a muscle: the areas that are used grow and improve while those which aren't, don't."

So getting the correct diagnosis is an important thing but having belief in your child and their unique potential; and helping them to develop it is just as important if not even more so.

I guess that most parents taking the time to read this newsletter have such positive attitudes anyway and so I am preaching to the converted as they say.

But thought it was an interesting topic to touch upon anyway.

If you want to read the full Washington Post article go to:

<http://www.washingtonpost.com/wp-dyn/content/article/2007/02/23/AR2007022301785.html>

Improving the class room environment for kids on the autistic spectrum.

Researchers at the University of Coventry in the UK have developed a new environment that is helping autistic children in schools through digital technology.

This new technology is in response to studies that show the huge range of sensory triggers for children on the spectrum.

It is based around the senses and the setting engages children through vision, sound, movement and touch.

Basically the class room is set up with interactive multi-media technology that allows the teacher to control the environment through easy to use software.

The system is made up of a computer, tailor made software, a projector, a video camera and sound speakers.

Then to provide a safe, neutral environment traditional classroom strip lighting is swapped for daylight bulbs and an LED lighting system.

Also hypo allergenic marmoleum flooring and a padded projection screen were installed.

The rooms are painted white, and black blinds block out light and noise from outside.

In trials (called Project Spectrum) of these specially adapted environments; children with ASD have been found to

be able to relate and communicate better with their peers.

They have also been found to be able to form a better relationship with their school routine and improve their performance in class.

Dr Andree Woodcock, from Coventry University's Design Ergonomics Applied Research Group, said:

"Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights.

Children with autism are often the 'invisible pupils', placed in inappropriate school environments that don't meet their needs.

Project Spectrum is the first affordable space that can provide all children with a safe environment that can become part of everyday life."

From what I understand this technology is not hugely expensive and certainly the basic ideas behind a lot of it is not.

The painting of rooms white and use of black blinds for example are easily applicable to home and school environments everywhere without necessarily needing to break the bank.

So it is certainly something for you to think about and particularly mention to your child's school as a possible way to improve their school experience.

To read more about this story go to:
<http://www.sciencedaily.com/releases/2007/03/070308090525.htm>

And you can get a copy of the research paper "Designing from requirements: a case study of Project Spectrum" by Woodcock, A, Georgiou, D, Jackson, J, and Woolner, A, from Jenny Murray.

Just email: jenny@communicationsmanagement.co.uk

Parenting Tip - Humming and boundaries

We recently received an email with a great tip from J. Glass about her 7 year old grandson with Aspergers.

"I would like to pass along a hint that we found worked great with our Aspergers grandson.

My husband and I pick up our grandson (7) and granddaughter (4) from school on occasion.

After spending the after school hours and dinner with us we drive them home.

Always on the drive home our grandson would hum driving his sister and I crazy and usually ending in a sibling fight.

We told our grandson that he could run around and hum as much as he wanted before he got into the car, but once in the car it had to be quiet with no humming.

It has worked amazingly and now they both sit quietly and listen to music, taking turns which song they like."

Now for some parents this may well be an approach that you are already using of sorts, but I wanted to mention this tip as it's a great basic behavioral approach that can really work.

Variations of this can involve for example using an egg timer to allow a child a certain amount of time to do a particular activity with a visual cue for when they need to stop.

So for some of you I hope you can try out this approach and for others perhaps a reminder to use such techniques to help everyone in the family.

So thanks again to J. Glass (I am sorry I don't know your first name) and I would love tips from other readers too that could benefit other people with their Aspergers child.

Jason McElwain - Basketball hero

Now I imagine for most of my American readers and other youtube fans this will not be breaking news for you.

But this month's famous autistic person that I have chosen is Jason McElwain.

Last year he featured on CBS as well as a ton of other news shows and internet sites around the world.

Jason was a 16 year old high school student in Rochester, New York diagnosed with high functioning autism.

Basketball mad Jason helped the coach out for several years as manager on the basketball team with all kinds of tasks, but never got to play.

Until he was finally given his chance to sit on the bench for the last game of the season.

He then got a chance to come on to the court and managed to hit 3 baskets in quick succession.

This has since propelled him to fame (and probable fortune) meeting George Bush, Magic Johnson, being given a host of awards (including "Best Sports Moment" by ESPN) and Columbia Pictures have built the film rights to his life story.

Now that is all very newsworthy and exciting but the thing that struck me most is the way that Jason seemed to be treated and respected in the school.

The fact that he was encouraged to be an active part of the team is an excellent demonstration of positive inclusion in a mainstream school of a child on the autistic spectrum.

Furthermore he seemed to be well respected and liked by pupils (he got a huge reception when he came on to the court) even before his 5 minutes of fame.

So Jason seemed to be a well loved and respected school member with a positive identity.

Which to me is the most heart-warming and exciting aspect of the story by far.

As for the Hollywood film I just pray that it's done in a real life and sensitive way that can help to inform and educate people about both the joys and challenges for children on the autistic spectrum and their parents.

And does not end up being some blockbuster that gives the completely unfair and untrue message that all kids with autism are potential basketball geniuses (or potential newsworthy geniuses of some kind in the "Rain Man" mode).

This kind of film gives the wrong impression to the general public of the realities of life for people on the autistic spectrum and their families.

To watch the video of Jason go to:

<http://www.collegehumor.com/video:1667265>

To read more about Jason on Wikipedia go to:

http://en.wikipedia.org/wiki/Jason_McElwain

Transporters DVD update part 3!

For several months we have talked about a free educational DVD available in the UK for children with ASD called "The Transporters".

Some of you non-Uk residents asked if I could help in getting a copy to you.

I have finally received my copy and it looked really good with a quick viewing this week.

My original plan was to burn off copies and send them to people who had requested a copy.

But.....I have just discovered that my computer's DVD Rom has only got a play function and cannot burn discs.

So back to the drawing board.....!

But if any readers in the UK who have a copy would be happy to burn one off and send to a parent overseas please contact me.

I am also investigating a website called "Bit Torrent" which I am reliably informed I can use to upload the DVD on to and then people all over the world can log on to it and watch it or download for free.

So technology-permitting I will get this done real soon.

When I do I will let you all know with a quick email update.

But whilst searching online to see if someone had already put The Transporters up there I found a post from a mother of an autistic child from Norway.

She has compiled a big list of free train games and film clips on trains for those of you with children who really like trains.

The website to go to is:

http://www.autism-pdd.net/forum/forum_posts.asp?TID=11839&PN=0&TPN=2

I have noticed that several of the Lego links don't seem to work but many of the others do.

So check it out.

Well that's all for this edition and I hope you enjoyed it.

And the next edition of the newsletter should be due in mid-April.

And as ever.....please send in any inspirational stories that you know of, any questions that you would like our team of experts to answer, any topics that you wish to be discussed and news stories that you want to share.

We will publish as many as we can.

Until next month.....

Best Wishes

John Hillage

<http://www.parentingaspergers.com>

Mail to: info@parentingaspergers.com

P.S. Please feel free to forward this newsletter to your friends.

Parenting Aspergers
Information Online,
PO Box 789, Portsmouth
PO1 9DY United Kingdom

The write of the material present in the “The Parenting Autism & Aspergers Newsletter” believes that a multi-disciplinary approach to parenting aspergers children is of extreme importance. This means combining the approaches of a wide variety of disciplines involved with aspergers children and their parents such as social workers, nurses, teachers, doctors, psychologists, psychiatrists, counsellors, speech therapists. Also it involves using the knowledge and information of parents them selves. The author recognizes that within scientific, educational, social and medical fields there are

widely divergent viewpoints and opinions. This material is written for the express purpose of sharing educational information gathered from the experiences of the author and other people in the areas mentioned above. None of the information contained in this email is intended to diagnose, prevent, treat, or cure aspergers, nor is it intended to prescribe any of the techniques, materials or concepts presented as a form of treatment for aspergers. Before beginning any practice relating to aspergers it is highly recommended that you first obtain the consent and advice of a qualified health, education or social care professional. Should you choose to make use of the information contained herein without first consulting a health, education or social care professional, you are prescribing for yourself, which is your inalienable right. However, the author assumes no responsibility for the choices you make after your review of the information contained herein and your consultation with a qualified health, education or social care professional. None of the statements in this article or in the book have been evaluated by the Food & Drug Administration (FDA), or the American Medical Association (AMA). This material is not warranted for any particular or general purpose whatsoever. Viewers of this material assume any and all risks for any use of this material. This material may not be reproduced in any way.

This email is never sent without permission

You are receiving this email because you or someone using your email address visited www.parentingaspergers.com and signed up for email information.

www.ParentingAspergers.com

The information we have on file is

Name: [[name]]

Email: [[email]]
