

PARENTING AUTISM & ASPERGERS NEWSLETTER
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A belated Happy New Year to you and welcome to the third edition of

"The Parenting Autism & Aspergers Newsletter"

Apologies to you all as we try to get the newsletter out by the middle of the month.

A few technical problems have made us a bit late this time.

But no matter here we go.....

Inside this edition you will find:

1. Hot Topic of Discussion – The new film "Autism Every day"
2. In the News – Fences for an autistic child.
3. Parenting Tips - How to survive a trip to the local store.
4. Famous Aspie - Gary Numan.
5. And Now For Something Completely Different - The Travelling Skunk!
6. Transporters DVD - Update.

I hope you enjoy this edition.....

Best Wishes

John Hillage

Autism Every Day:

On Sunday 21st January the film "Autism Every Day" had it's first screening at The SunDance Film Festival.

It is scheduled for further showings on January 22nd and 27th, in Utah.

The film is a 44 minute documentary that looks into the lives of families and their autistic children.

Not being part of the Hollywood elite set I have not yet seen the film!

But the summary provided by Autism Speaks sounds like this film is going to be a very true and honest account of what families and their children experience every day.

The film covers families from both the high and low ends of the financial spectrum and from a variety of different ethnic backgrounds.

Which again sounds promising for a full and informative picture.

Although reading between the lines of the website I think the film may focus on children with severe autism and related learning disabilities.

Rather than children with High Functioning Autism/Aspergers - but I may be wrong on that.

The documentary has evolved out of an original 12 minute film made to help Autism Speaks' fundraising.

You may well have seen this already as it went all over the internet as a viral video for some time.

Well as far as I can tell the film sounds like a really good thing and will no doubt open up a lot of discussion in the media about autism.

If it is screened at cinemas at a future date this can only help further with educating the public at large about autism and what having an autistic child really means.

It's so important to get those discussions out there and present realistic images of what it is like to have an autistic child.

As most of society is still very ignorant about autism (although this is becoming less so as more and more families are being touched by autism).

And this film sounds like it will be an accurate portrayal, which is a good thing.

I remember seeing Rain Man when I was much younger and had no real understanding of autism.

I came away thinking for years that all autistic people had phenomenal skills with numbers and constantly repeated "I'm a very good driver" to themselves and anyone who would listen.

That's the power of the media - and as you will all know the similarities of Dustin Hoffman and what you experience on a day-to-day basis are pretty limited.

And don't even get me started on Tom Cruise.....!

So thumbs up to the release of a real-life autism film into the mainstream.

But I guess I will reserve judgement on the content until I have seen it.

Perhaps when it's been out on general release we could share comments and thoughts from some of you guys on the film and what it was really like.

Fences for an autistic child

This news story comes from Littleton, in the Rocky Mountains, USA.

It kind of follows on from the theme of public ignorance about autism and the effects on a family of having an autistic child.

A couple (called the Illigs) live in Littleton and have an 8 year old son who is a "runner" (this is a phrase used a lot where I work but don't know if it's universal or not).

But to explain a "runner" is a child who you have concerns about simply dashing off when not supervised without any real road sense or street wise knowledge.

In consultation with the appropriate professionals the Illigs had a higher fence put up around their property to ensure that their son did not climb over and out into the street - where he would be at real risk on his own.

The fence were similar in size to the others around the neighborhood, so all seemed to be going well.

The new fence would help keep their son safe and did not look out of place.

However in stepped the local homeowners association who wrote to the family to ask them to tear down the fence or modify it as it wasn't approved by them and there had been "complaints".

Now the big "unthinkable" sin that had been committed by the Illigs was that instead of a dark wood fence like the others' they had "dared" to use tan cedar wood.....!

I am speechless that the so-called neighborhood association feel that it is OK to put their personal decor preferences over the health and safety of a very vulnerable young child.

How ridiculous and unthinking can you be.

Doesn't it just warm your heart right through?!

Perhaps spending an hour or so baby-sitting for this young boy would help these "neighbors" (in the most loose sense of the word) get a much-needed change to their Ikea-obsessed perspective!

The good news is that other neighbors have since offered their support to the family - so it seems that it's just a few power-crazed local officials are behind this particular brand of kindness and humanity.....

But if ever there was a time for a new film to educate the public about the effects on a family of having an autistic child.....

To read the whole story go to:

http://www.rockymountainnews.com/drmn/local/article/0,1299,DRMN_15_5212952,00.html

Parenting Tip - Toileting problems

Unfortunately following on from Erin Bailey's excellent parenting tip about "helping your child in the store" we did not get any more tips to share this month.

So please if you have any useful parenting hints or tips to share email us so that we can share the information that may be able to help others.

Or if you have an issue or question that you want us to answer please let us know.

So instead this month I have included a problem that we recently advised a parent on:

PROBLEM

"My son is in 4th grade and he has social issues, is very clumsy and does not play sports.

His latest problem at school is going to the bathroom and being extremely loud and singing and when he comes out the kids are laughing at him.

I tried to explain to him that he can do this at home but in social situations it is best to be quiet in the bathroom.

He says he agrees with me but does it again the next day and the kids laugh again.

He cannot pick up on non-verbal clues and is also the most ADD child I have ever met.

It takes an hour to put on PJ's.

He is so distracted by everything in his way."

SOLUTION

"As always in these situations it is important to unpick the problem before attempting to remedy the situation.

With regard to the toileting it seems there are several issues here.

One is the lack of understanding of social conventions in the toilet and the second is the problem in remembering.

The third difficulty you talk about is the sensory issues which leads me to think that shouting in the toilet may be also linked to this.

Remember that all behaviour has a purpose and at some level this behaviour meets a purpose and it could be fulfilling some sensory need.

It may also be provoked by fear (quite common in ASD kids who can be afraid of the noises associated with toilets, water flushing etc).

His loud behaviours may be an attempt to 'cover up' these noises.

Assuming these are all part of the problem it becomes easier to tackle.

The first part can be tackled by pre teaching the routine through a social story using a series of simple pictures and sentences (see thegraycenter.org for more on this).

The story should be read every day to remind your son of the expected behaviour.

He will find this easier to remember than just a set of oral instructions

The sensory issues need to be approached rather differently.

Your son will possibly need a replacement activity and this often needs to be a modified form of the initial behaviour for him to manage.

If he shouts now he can be taught to 'hum'.

Additionally he could be encouraged to go into the toilets at a quieter time when no other children are there.

He is less likely to draw attention to himself at these times.

You may need to talk to his teacher to engineer these opportunities as when children all turn out of class and end up in there at the same time it can be very noisy and possibly quite scary for your son.

Once you begin to break down this behaviour into some smaller chunks you will begin to see where the flash points are, once you can pinpoint the issues like this you are half way to solving the problem.

Gary Numan - 1980's pop star and aspie....

Gary Numan is a pop star who was born in London, UK in 1957.

He had a number of hits in the late 1970's and 1980's.

With perhaps his most famous being "Cars" which was a big hit in the UK and also made the Top 10 in the USA in 1980.

This was an electronic record that I am sure a lot of you will remember (to remind yourself listen to a free sample at: <http://www.smokecds.com/track/200103>)

He has continued to record since then and has completed over 30 albums and has another planned for 2007.

And many musicians have sung his praises from as diverse as Davie Bowie, Marilyn Manson, Beck and David Grohl (from The Foo Fighters and Nirvana).

It was not until he was an adult that he realised that he had a mild form of Asperger's.

It was recognised by his wife and in an interview in 2001 with The Sunday Times he said

"Polite conversation has never been one of my strong points.

Just recently I actually found out that I'd got a mild form of Asperger's Syndrome which basically means I have trouble interacting with people.

For years, I couldn't understand why people thought I was arrogant, but now it all makes a bit more sense."

Like many people of his generation it was suspected that something was a little "different" about Gary but not enough was really known or done about it at that time.

In another interview when asked about Aspergers he said

"It was suggested I had it when I was younger but no one knew much about it then.

I've read a lot about it since and I fulfil some of the diagnostic criteria but not others.

I probably have a mild form...for example, if people came over for dinner and I saw a magazine I hadn't read, I'd pick it up, sit in the corner and read it - which I now know is wrong..."

There is debate online as to whether Gary is officially or self-diagnosed with Asperger's.

Either way he is clearly someone who has managed to sustain a career in the music industry for 30 years with some degree of Aspergers.

Which is no mean feat!

And Now for Something Completely Different . . .

A stowaway skunk recently made a break for the border when he travelled from California to Toronto, Canada in the back of a truck.

It is believed that he fell asleep in the back of a truck in a yard in California and then 2200 miles later was discovered in Canada.

The good folk at The Toronto Wildlife Center have been looking after him since January 5th until they could find a person stupid enough (oops- I mean kind enough!) to give him a lift home.

But now a kind couple have agreed to take the animal back to the US for an official handover to the US Fish and Wildlife Service at the Border.

So he's off home real soon.

I just hope their automatic car windows are working.....
they must just need them!

Transporters DVD update

This month I sent you information about a free educational DVD available in the UK for children with ASD called "The Transporters".

A number of non-UK residents have emailed to see if they could get a copy.

I was hoping that some of our UK readers who have got a copy would be happy to burn off a copy and send it to our non-UK readers, in return for the cost of postage and packing.

This would also be a great way of parents from across the world being able to build a relationship, chat and discuss issues with each other by email.

So if anyone from the UK is able to help with this please email me and we can take it from there.

Thanks

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

But I would really like to hear back from you about the content of the newsletter.

Several people have said that they are not really interested in the "Famous Autistics" and "Now For Something Completely Different" sections.

If that's the case for most of our readers we will take them out - but we don't know unless you tell us.

Please look out in your in-box for the next newsletter in mid-February time.

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.
