



Aspiehelp / The Aspire Trust March 2018 Newsletter

Edited by Anna Melling

Motueka Roadshow, Mayan in London, The Box - Emma Goodall, Harry Josephine Giles, BBC Article on Women with Late Diagnoses, "Are we speaking the same language?"

Motueka Roadshow

Leith and Julie will be doing a public presentation/Q&A in Motueka. This will be at **7pm on Thursday 5th April**. Location is the **Motueka Community House, Decks Reserve** (same carpark as the Info Centre). Admission by donation.

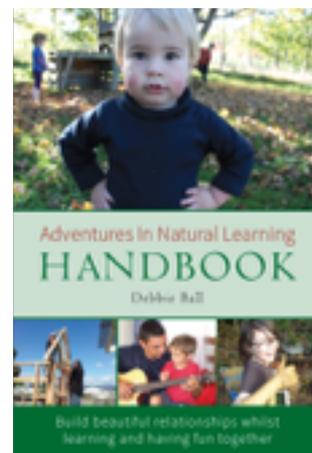
This is for anyone who is interested, aspies, families, friends, teachers and employers alike.



Debbie Ball will be there from 6:30. Debbie is a local author, artist and home educating mother. She seeks to encourage others to build strong relationships with the children in their care, and is passionate about alternative education methods for those who don't fit into mainstream.

She does this through her Facebook page, blog and also the Adventures In Natural Learning Handbook which she will have for sale on the night. Her postcard colouring books will be available also.

<http://adventuresinnaturallearning.blogspot.co.nz/>



We have some spaces for appointments on Thursday or Friday. We do have to charge fees of \$150.00 plus membership of \$30.00 for 2018-19.

No Social Night on the 5th of April

Due to Leith and Julie's trip, there is no social night on the 5th of April.

Upcoming Fundraising Sausage Sizzles

Here are the dates for the upcoming Sausage Sizzles at Fresh Meats Barrington (Barrington Mall):

Saturday the 31st of March
Saturday the 28th of April
Saturday the 12th of May
Saturday the 26th of May

If you're in the area, come and visit, say hello and perhaps buy a sausage! We are always grateful for volunteers to help out with the sausage sizzles, even 2 hours now and then is very helpful (contact the office in advance if you want to help out)

In Our Office

We had a meeting with our two favourite Psychologists, Charlotte West and Dr Olive Webb (an old classmate of Leith's!) and shared some important information about how we can work together. Later we met another psychologist, Kaye Wolland, from Whakatata House, a new and mutually rewarding connection.

The same day, we went to a meeting at Burwood Hospital about setting up a Welfare Guardianship organisation in Christchurch, which sounded very positive.

Julie attended a COGS meeting (Community Grants Scheme) and Leith attended a meeting at the workplace of one of our clients and changed the attitude of the employers somewhat.

We have NEW BLINDS in the office! Lovely mini Venetians to filter the bright outdoor light!

We also had to do a rush assessment of a Corrections client last thing on a Thursday for his court appearance the next morning!

The next day Julie and Leith visited Open Day at the Loft, a huge service centre in the Eastgate building, and left pamphlets. It is ENORMOUS and a bit intimidating! While there we met our colleagues from Autism Canterbury, which was nice.

Leith has been chosen as one of the members of an AutismNZ Consumer panel, whose first meeting was conducted by Conference Call. Her outspokenness seemed to surprise the Co-ordinator but everyone else said "hear hear"!

Further development of services to help particularly challenging clients continues. We believe we are making progress. On the other hand, Hillmorton Hospital continues to turn people away when they really, really want a bit more help. Gahh!

Next month we are making a quick trip to the Tasman District to see friends/family and present an information evening. We must also make an approach to Carmel Sepuloni MP about Asperger Syndrome Services and also the CDHB!



*Our staff from top:
Leith, Julie, and Anna*

Social evenings

Our regular social evenings are on the first and the third Wednesday of the month, in Cashmere from 7pm - 9pm.

We have board games, hot drinks and biscuits, and a selection of books from the Aspiehelp library available at every meeting. Please bring a \$2 donation.

The next meetings are on the 18th of April and the 2nd of May.

Aspiring members should make an appointment to meet Julie and Leith first.

Our Patron is Stephen Mark Shore, PhD.

The Aspire Trust, Inc is a registered Charitable Trust. Charities Services registration number is CC46192.

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Mayan in London

(Story written with Mayan's permission). Mayan was a client from last year and when we met her first she was very depressed, We made a few recommendations and saw her intermittently through 2017, as she improved impressively.

Early this year, Mayan was planning to fly to London to receive more training in her chosen employment but was worried about travelling on her own. Leith recommended that Mayan inform the airlines of her autism with the following result:

"Thank you so much for your help and advice for Mayan's travel. She managed to get to London on her own (a bit of drama with a panic attack and faint from Melbourne to Dubai, but a helpful doctor on board provided assistance).

Qantas staff helped her at each destination (ChCh, Melbourne, Dubai and London) which made it all possible. It seems like airlines are really upping their game with understanding the difficulties with autism. Heathrow have a whole section on their website about hidden disabilities and provide sunflower lanyards to alert staff that a passenger is autistic".

So - a bit of good news if anyone is interested in travelling overseas- alert the airline staff and ask for assistance whenever you need it.

Hidden Disability Sunflower Lanyards

If you're travelling in the UK, most airports can provide Sunflower Lanyards to indicate to staff that you have a hidden disability.

Heathrow's website says:

"By wearing one of our Sunflower Lanyards, it will discreetly indicate to our staff that you have a hidden disability and you would like additional support. Our staff have been trained to recognise these lanyards, and to provide you with any help you may need at various stage at the airport.

"All you need to do to get one of our Sunflower Lanyards simply email us at: special_assistance@heathrow.com and provide us with a forwarding address."



The Box - Emma Goodall

It is often said that of the great things about autistics is our ability to think outside the box, which is true, but it is because we rarely see this type of box. The box that can sometimes/often frame us is the mime's box. Thick plexiglass on all six sides, we can see and hear through it but we cannot connect through it, so the stark sense of loneliness is brought into that awful place of lonely even when around others.

Intellectual problems or other people's problems are liberating, they help the focus away from the mime's trap and into the wider universe of possibilities. Even problem solving and I can even forget that I am suspended in that universe in Marcel Marceau's gift to the world. A bittersweet gift that I would like to think of a way to remove permanently.

Harry Josephine Giles

Harry Giles is a performer, poet and, in the author's words, 'a general doer of things', and is also on the spectrum. They were in New Zealand recently for the Writers Festival.



Harry did an interview with Radio New Zealand, which can be found at the following link for those interested:

<https://www.radionz.co.nz/national/programmes/saturday/audio/2018635528/harry-giles-fun-and-games>

BBC Article - It all made sense when we found out we were autistic

http://www.bbc.co.uk/news/resources/idt-sh/women_late_diagnosis_autism



An interesting article from the BBC about women receiving diagnoses later in life. Excerpt follows:

About 700,000 people in the UK are on the autism spectrum, according to the National Autistic Society
Five times as many males as females are diagnosed
Autism is under-diagnosed in females

"I'm Maura Campbell.

I was born with the social skills of a used teabag."

"That's how I described myself at the BBC Ouch storytelling event at the Edinburgh Festival Fringe last year.

I'm now 50. Six years ago I was diagnosed with Asperger syndrome, a form of autism. Like many women, this came after the diagnosis of my son, Darragh.

If it wasn't for this, I'd have gone through the rest of my life unaware of why I felt different.

As a child I'd felt as though everyone but me had been given a manual on how to behave around other people.

I was more comfortable around pets. Because I performed well academically and masked my anxiety, I flew under the radar.

People assumed I was just shy.

When my autism was identified, it felt like taking off a corset I didn't know I'd been wearing...

Women do not need to fear a diagnosis - it may help explain so much. Whether to disclose it is, of course, a personal choice...

Since Edinburgh, I've continued writing about autism and disability and had several articles published.

I've co-authored a book along with some of my autistic sisters from around the globe, some of whom have become close friends...

"Keep scrolling to meet six other women who - like me - only found out they were on the spectrum when they reached adulthood."

‘ARE WE SPEAKING THE SAME LANGUAGE?’ – WHY AUTISTIC COMMUNICATION ISN’T ‘WRONG’

Jeanette Purkis

Republished with permission from

<https://jeanettepurkis.wordpress.com/2018/03/24/are-we-speaking-the-same-language-why-autistic-cmmunciation-isnt-wrong/>



Apparently I get communication ‘wrong’ sometimes when interacting with neurotypical people. They tell me I am coming across in a way which is upsetting for them or confusing or a range of other things. However when I think about my intentions from the same conversations I am aware what the other person received was a long way off what I was intending to convey. This always leaves my doubting myself and feeling bad. In fact it shouldn’t. I expressed what I wanted to clearly but between Autistic me and the neurotypical person I was speaking with, the message somehow got lost in translation. I didn’t do anything ‘wrong’ and neither did they. It is just that we communicate differently. Autistic communication tends to not be understood as such. Instead we are viewed as if we were neurotypical people communicating really poorly.

This lack of understanding communication can result in discrimination against Autistic people. Neurodiversity is a relatively new concept. When it comes to communication differences, someone doesn’t only need to be speaking a different language like French or Japanese, they can ‘speak’ the language of a different type of neurology. Not everyone communicates in the neurotypical ‘language’. In addition to this, every single one of us sees the world through the lens of our own experience. Autistic people do, neurotypical people do – everyone does. This makes it hard for people to see that someone else might be communicating from a different perspective. I find autistics tend to be better at being aware of this than neurotypical people. This is possibly because being a minority in terms of communication we have had to ‘learn’ the language of expressing meaning used by our allistic colleagues and peers.

Our different Autistic ‘language’ has almost always been seen as wrong. The basis of ABA and similar ‘therapies’ for Autistic kids is in this idea that we communicate wrong. Apparently, if we just looked ‘less autistic’ and ‘fitted in better’ our lives would improved. In actual fact these sort of ‘therapies’ are often really harmful and do a lot more to make us doubt and dislike ourselves than offer anything very useful in terms of communication.

Imagine a nation where there is a colonial occupation and the people in that nation are forced to speak the language of the colonial power – English, Spanish etc. I liken this to making Autistic people change their communication in order to be seen as communicating the same way as the others (‘The right way’ apparently.) I have huge issues with this. I’m happy to (figuratively) learn Spanish but it needs to be on my terms not because I’m forced to conform. There is really nothing wrong with my Autistic ‘language’.

Some of the key areas where communication and expression differences happen include:

- Honesty. Autistic people tend to be honest by default. Lying is difficult or impossible for many of us. In terms of communication style this means we tend to be very direct and

upfront. Many neurotypical people see this as rudeness or us being needlessly blunt. Conversely many Autistic people dislike the 'dishonesty' (e.g. white lies, omissions etc) we see in our allistic peers which for them is just usual communication.

- Manipulation and subterfuge. Autistic people often operate only on one level. There is usually no subterfuge or hidden meaning beneath what we say and do. This is often misinterpreted by neurotypical people who do tend to operate on more than one level so assume we do too. Not being aware of and respecting this difference can be really confusing and damage relationships.
- Nonverbal cues. Autistic people are often not focussed on others' body language. Many of us don't really know what it is meant to be conveying. Non-autistic people can also misinterpret our own non-verbal signals. This can impact on things like the perception of empathy. I can't really tell if somebody is sad unless they are crying, and even then I may miss it. I have a lot of empathy and if I know someone is having a hard time I will be there for them as much as I can but this can get missed leading to accusations that I am uncaring.
- Communication and alexithymia. This is also known as emotion blindness. Many autistics experience this and it can make life very difficult, including around perceived meaning. I sometimes don't realise how forthright something I say seems until afterwards as I wasn't aware I felt passionate, or angry or sad etc. When challenged on being too forceful on one occasion I advised I wasn't and it must have come out wrong but afterwards when I interrogated my memory of the exchange I realised I had been quite upset, I just hadn't noticed at the time. Imagine trying to explain that to somebody who didn't understand the differences I was talking about? I think I was seen as being dishonest and making excuses.

It is hard to go through life being misunderstood and judged. It is one of the reasons that I value spending time with my Autistic peers – my tribe if you like. I am acutely aware that I am speaking a different language with non-autistic people but often they just don't realise it.

This is a key issue for Autistic people navigating the world. There are solutions and I think a lot of these revolve around increased focus on the value of difference and basically applying the concept of 'different not less' in interactions between people, Autistic, non-autistic and everyone else!

I would love to support neurotypical people learn to 'speak Autistic' more. In fact I think a lot of my work falls into that category.

There are many ways to communicate. Learning the language of another person gives you views into their understanding, their culture and their being,

