

Sabbatical Report Term 2, 2019



Written by:

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I firstly would like to thank my Board of Trustees, particularly my Board Chair, for supporting my application and thereafter the Teaching NZ entity, for accepting the same.

Secondly, the following schools who allowed me to observe and discuss Autistic Girls both in Special Needs Schools' settings, and within Mainstream Schools:

Tauranga Special School

Goldfields Special School/Paeroa

Welcome Bay School Tauranga

Tauranga Intermediate

Te Puna Primary Tauranga

Aorangi Primary School, Rotorua

Taumata Primary School Tauranga

Earl Childhood Centre: Above and
Beyond/Tauranga

Thirdly to my Deputy Principal, Acting
Principal in my absence, G. Hughes for her
leadership at our school in my absence.

Without the support of you all, my research
focus and study. would have been
unattainable.

My topic:

GIRLS with AUTISM

The Maori word for Autism is:

“TAKIWATANGA”

This means

“In his/her own time and space”.

Autism and Girls: what we thought we knew

Autism is a relative recent diagnosis, although there is little doubt that there have always been autistic people (see Houston and Frith 2000 for a historical case study).

If you visit any Special Needs school in NZ, usually there are more boys than girls with a diagnosis of Autism.

The question is why?

In 2018 I attended an Australasian Conference for Special Needs colleagues and other interested people in mental health in education, held in Adelaide.

One of the sessions facilitated by Professor Barry Carpenter, was about Girls with Autism.

Barry Carpenter, CBE, OBE, is a professor of mental health in Education at Oxford Brookes University, UK.

Barry is well known for his knowledge and expertise here in NZ and globally, amongst our Special Needs School community.

This lecture/seminar by Barry piqued my interest in the first instance.

I felt I knew quite a lot about the girls whom have been diagnosed with Autism in our Special Needs school, but I also wanted to observe and interview girls in Mainstream schools, i.e. with Autism but without the intellectual disability.

The other driving force was that when I applied for this Sabbatical there were signs that our granddaughter may be Autistic.

Historical background

It is amazing that, 30 years after its release, the film Rain Man still sets the bar for what we understand about autism: boys and men who are extremely good at maths and do not understand other people. It is a movie based on the work of male scientists like Leo Kanner, who thought autism was mothers' fault for failing to love their children enough;

of Hans Asperger, who thought no women or girls were affected by the syndrome he identified, and shored up by the work of Simon Baron-Cohen, who theorized that male and female brains are fundamentally different-men are better at systemizing, women at empathizing-and therefore autism is an 'extreme of the male brain'.

This template and belief not only trapped generations of men in cliché, but also prevented thousands of girls and women getting support and understanding they need because a male gaze simply never saw them.

What I discovered was that every experience of Autism is unique. No one person will identify with every positive feature of Autism. We all have individual skills, attributes and characteristics that are as unique as our personalities.

This is the power of neurodiversity.

Some findings

Autism has long been thought of as a predominately 'male' disorder, autism has long gone unnoticed and unsupported in girls- sometimes with devastating consequences for their social and mental well-being. Current research reveals a much more balanced male-to-female ratio in autism, helping professionals to recognize, understand, support and teach them effectively.

Girls have historically been overlooked by traditional diagnostic approaches, identifying behaviours that may be particular to girls, and exploring the camouflaging, that can make the diagnosis of girls more difficult.

For people with autism, trying to understand the rest of us can feel like travelling to another country-learning another language and navigating a new landscape, while brandishing a passport that allows them access.....but not acceptance.

For women and girls with autism, it is more like sneaking into the same country under the cover of darkness, wearing a disguise during the daytime and hoping every moment that no one blows your cover.

Because often girls show shyness and no behaviour problems plus can be very quiet and seem to float into the woodwork.....they are not so blatantly noticed c.f. with say a boy with behaviour problems.

Many girls (mainstream setting), have said they learnt from a young age, which girl to emulate to be accepted and how they yearned to be part of the 'cool', crowd so learn quickly what to say or how to behave. This places more anxiety on them and although they may make it through the school day they can have explosive meltdowns at home. They become very adept at mimicking

the expected behaviour of the neurotypical women and girls, adopting social stereotypes to be quiet and biddable, which create an unbearable mental strain.

Forty years ago it was believed that the ratio of men with autism to women was 15-1. In 2015 data from the National Autistic Society suggested it could be 3-1.

Girls may be overlooked merely because their behaviours are often easily managed and not disruptive and noisy as boys can be. They may also go unnoticed in a crowded classroom.

Girls may present as more quirky, odd or unusual, rather than troublesome and problematic. Some girls may feel more at ease with adults too, rather than their peer group.

Often the natural temperament of girls may mask milder forms of Autism.

Despite the difference in reported numbers, females on the Autism Spectrum are well

represented by women who have written with great insight and clarity about their experiences. Donna Williams and Temple Grandin are two that spring to mind. They have brought the experience of being on the spectrum to the fore and even popularised awareness and are able to describe their own understanding of Autism. The ability of women to describe their own experience is something that distinguishes them favourably to their male counterparts. This has also been very valuable in bringing understanding, support and a reduction of isolation to others.

Early recognition leading to referral for assessment in childhood is usually based on problem behaviour, abnormal social functioning or due to co morbidities such as ADHD and Dyslexia leading to academic problems. Males are much more commonly referred due to their odd sometimes

aggressive or disruptive behaviours, and problems with social functioning.

This comes to the attention of the teachers and parents more readily than in girls.

One young girl in a Mainstream school said:

“When I was little I said I liked Pink and princesses because girls around me said they did. But I felt uncomfortable because I didn’t like it and I didn’t understand why I was supposed to.”

In mainstream schools, girls on the autism spectrum are frequently overlooked for support especially if they have intellectual functioning in the average range. As Baldwin and Costley (2016) observe, does not equate to an absence of learning support needs’.

Just because the girls aren't obsessed with Thomas the Tank Engine and lining up things in neat rows doesn't mean they are not on the spectrum. Just because they may make eye contact, have a reciprocal conversation with someone for five minutes and exchange small pleasantries doesn't mean they are not autistic.

It means they have learnt to do it. We have to redefine what autism is.

(Lee-Potter 2016)

Often some girls become the quiet, anxious student who will tend to sit at the back of the classroom, (mainstream), concealing their difficulties behind a socially acceptable mask.

(Tierney et al. 2016)

The way forward

Overwhelmingly my study has shown a huge need for professionals, indeed all whom are in contact with girls with autism to have support and training in what is autism and how to support it in the classroom and onto their lives outside of schooling.

The teachers whom I spoke with have a limited knowledge of Autism and the scant information related to the huge variance of behaviours and strategies required to support those young people.

Professionals need information to better understand girls on the autism spectrum, enabling them to recognize, understand, refer, support and teach autistic girls effectively.

To avoid bleak outcomes, autistic girls need a timely diagnosis, followed by an in-depth

needs assessment leading to relevant personalised interventions in the areas of education, social skills and communication. Without this scaffolding, these girls are in danger of growing up to be women who remain undiagnosed, without employment, having no social contacts outside of the family.....and almost wholly dependent on their parents to support them in their everyday living.

(Gould and Ashton-Smith 2012).

Some points that emerged are as follows:

- Girls are on average diagnosed at a later age than boys (Berger et.al. 2013)
- Girls are less likely to be diagnosed than boys (Dworzynski 2012).
- Some girls may show their autism differently from classic male presentation

when they show the same level of behaviour symptoms (Russell 2011).

- Girls more than boys, need additional red flags (such as intellectual disability or behavioural problems) to get identified for autism diagnosis.
- Girls narrow special interests may appear more neurotypical (e.g. horses, boy bands, versus electricity pylons; Sutherland 2017).
- Social differences may show in a 'clingy' rather than 'aloof' style on interaction. (Kopp and Gilbert 1992); and
- In the playground, girls on the spectrum look less conspicuous and less different/isolated from their peers than boys on the spectrum.

Many girls and women on the spectrum describe 'masking' or camouflaging' their autism (Dean 2017).

Gender role expectations may lead females on the autism spectrum to modify their behaviour (e.g. copying the behaviour, clothes and voice of a popular classmate); and Camouflaging or compensating to fit in with neurotypical expectations is described by many autistic girls as exhausting, and may have negative consequences for mental health (Livingston 2018).

Looking ahead

Utilizing interests and strengths is the best way forward in autism. Finding ways to explore the hidden curriculum of any social society is made so much easier and available when individuals can access it via their interests. When individuals on the spectrum are not interested, motivation is switched off.

Working together within individual interests is the remedy for this.

Professionals cannot afford to remain ignorant any longer. We have no excuses for not acting on our given knowledge. At least 50% of the population is female, and there must be a response from us to this urgent call to action.

Myths and truths to consider for some girls when wondering about the autism spectrum

1. She is too social to be autistic. She has friends or wants to have friends so she cannot be autistic. MYTH
2. She looks at me when I speak to her, so she cannot be autistic. MYTH
3. Girls follow the rules-they are less likely to act out due to the need to please others. TRUE

4. Girls will mimic others to fit in- and their true difficulties are often overlooked because of this. TRUE
5. Girls find communicating their feelings unavailable to them and may become mute within the classroom, despite talking at home. TRUE
6. Some girls may not want to be the centre of attention or have the spotlight on them. TRUE Others love the spotlight! Also TRUE
7. Girls may have a love of technology, horses, animals, reading and/or friends. TRUE
8. Some girls may live their lives through others and find personal autonomy elusive. TRUE
9. Some girls live with severe anxiety. TRUE
10. Many girls have performance issues and will not settle for less than perfect. TRUE
11. Girls may be unable to stop certain behaviours-having to twirl or spin, pick

- at their fingers, scrunch up their toes or face, have a need to twitch. TRUE
12. Girls need to tune into their cues and follow them strictly to know what comes next. TRUE
 13. Girls find it difficult to process lots of information at once. They need to do one thing at a time. TRUE
 14. Girls need consistency, structure and continuity. TRUE
 15. Girls exhibit rigid behaviours and resist change. TRUE Also TRUE though, some girls do not have an issue with change.
 16. Routine is very important to girls and if it changes they need to have this visually presented or written down. TRUE
 17. Girls find body language and facial expressions difficult to read. TRUE
 18. Girls often have an inability to understand jokes or make jokes that others do not understand. TRUE

19. Girls need to have others explain in many different ways what is happening and how things work. It is important to try Tube video or asking Google works a treat! TRUE
20. LOTS and LOTS of questions about life are often repeated and answers fail to make sense. TRUE
21. Girls show an inability to move on and let negatives go; they fixate on stuff and do not know how to process this or let it go. TRUE
22. In school, girls are often missed as they appear to be conforming. The TEACHERS AND Professionals do not see the issues that are going on at home-the lack of sleep, the outbursts, the lack of understanding. Professionals must listen to parents and parents have to take notes and document what is happening. TRUE

All schools must be inclusive.

A car may use Petrol/Diesel or Electricity.....but all can reach their respective destination.

Case Study

I have been privileged to observe and interact with a young child/girl at an Early Childhood Centre transitioning to Primary School (Mainstream), when she turned 5 this year.

Family and staff at the Centre had, noticed they young girl preferred to play on her own, initially parallel playing, had difficulty nor showing any

desire to join into the group, but preferred to sit on the periphery of the class and not being communicative. Her behaviour was not unruly but had the glimmerings of Autism. Her mother was a very shy girl at the same age and the family thought maybe this child was too.

She gradually formed one or two close friendships and loved to play outdoors and be involved in art activities where she displayed long stints of total concentration. Her shyness was very apparent with a reluctance to make eye contact and being very clingy to her family. Once she knew you she

would hold eye contact. She is very affectionate with family.

Unfortunately, the Centre has several changes of staff during this time which totally unsettled the little girl.

There were fears she would not be ready to transition to school once she turned 5.

During this time, she had hearing and vision tests which proved no defect.

Her speech was delayed and her mother had had an extremely difficult birth which the Doctors and other Clinicians took note of. It is interesting to note that whilst attending Professor Barry Carpenter's seminar in Auckland in late June; he referred to mothers' whom had difficult deliveries with their

babies and how Speech can be delayed as a result.

Family on the Maternal side were/are all teachers and the little girl was receiving great support outside of the Centre in her everyday life.

A Speech Language Therapist and Occupational Therapist observed her during this time at the ECC.

Finally, she was assessed and found to have “mild to moderate Autism Spectrum Disorder” by Clinical Psychologists/Paediatrics, assisted by other Multi-Disciplinarian assessors.

The whole process took nigh on 9 months. She does not have an intellectual disability however.

The assessment was a total relief for the family and they now planned for her entry into mainstream.

Fortunately, a group of children from her Early Childhood Centre were placed in the same class.

The school that she moved to is a new school opened this very year in term1. The family were anxious as the classes were not single cell ones but open areas (MLE) with a variety of personnel and students housed in the new spaces.

The Mother has liaised closely with the school and I am delighted to learn that

the teacher had been to PD about Autism as well.

Much emphasis is placed upon Play Based learning so at this stage the little one is happy and does not resist going to school. She still has 1 or 2 only close friendships and does not like any change of routine.

This week, today she has refused to participate in the class photo, but no preparation and forewarning was done which is essential for a child with Autism.

She loves playing on the school playground

but shies away very anxiously from any hullabaloo from boys who are just being boys. As with Autism she reacts to sensory overload. If a boy plays chasey to her she becomes anxious and hides behind a familiar adult.

Her father takes her to school each morning and she will hide behind him if there are strangers approaching. At day's end she looks very anxiously for a familiar face, to reassure her that she will be picked.

Fortunately, she will wear the school uniform bar one item.....as with sensory issues the texture of materials can be problem some for Autistic people. (and food).

As she clamors up in sharing news time, being very anxious to speak in front of the others, the Mother and grandmother now take photos of what she does in the weekend/holidays, emails the same to the class teacher who now has a common reference point to encourage the child to speak about her experiences, which now she happily does so in a small group situation.

I have learnt in my role as teacher and Principal, that children are very accepting of classmates when they are young but tend to notice “differences”

more markedly as the child grows older.

Bullying can take place.

There is a mind-set that people will “grow out” of their condition. No, they learn to cope but always have the condition minute or otherwise.

The family is very watchful of her progress and encourage and support the staff as much as possible.

Inclusiveness is paramount.

She attends Swimming (1-1) and has started dance once a week which she loves.

She enjoys physical activity and ran the recent Cross Country which was an achievement despite the fact she was waiting for her close friends to catch up!

Every child has the right to be valued.

This little girl is my only grandchild.