

ALTOGETHER AUTISM
JOURNAL
ISSUE 1 2016

Our 'Help or Harm' issue

Robots helping children?

NeuroTribes reviewed

**Spotting fad
interventions**

**How to get help
with NCEA**

**ALTOGETHER
AUTISM**



Da Vinci Mechanics

27 February - 29 May 2016

Explore the mind of the greatest genius of all time

On loan from the museum of Leonardo da Vinci in Florence, Italy, this amazing exhibition brings together creations and concepts devised more than 500 years ago by the brilliant scientist, inventor and artist Leonardo da Vinci.

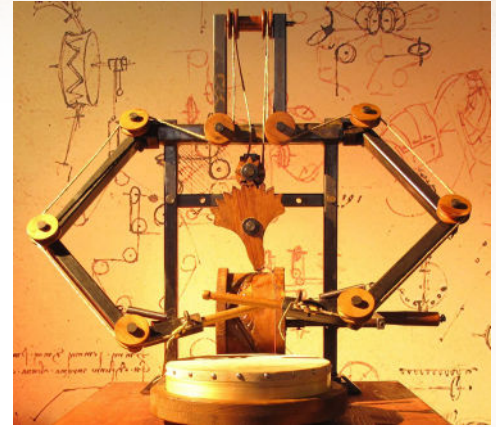
Da Vinci Mechanics is a display of precise and interactive replicas of machines and robotics designed and described by Leonardo da Vinci in the 15th century and hand-built in Italy.

With more than 80 machines and artworks on display, many of which are interactive, the collection brings to life the most important and impressive designs of the original Renaissance Man, including the bicycle, hang glider, helicopter, a mechanical lion and the incredible robot drummer.

Visitors to the exhibition will be invited to touch and handle the models to gain a first-hand appreciation of how they work. Interactive displays and items will be accompanied by explanatory notes and illustrative panels featuring da Vinci's drawings.

The exhibition also features children's activities, computer animations, a cinema and reproductions of Leonardo's greatest paintings.

Da Vinci Mechanics is a touring exhibition developed by Artisans of Florence.



World Autism Awareness Day - Autism-friendly sessions

To celebrate World Autism Awareness Day, Waikato Museum will present an autism-friendly evening session on **Saturday 2 April, 5pm-6.30pm**.

The museum recently consulted with Altogether Autism and is adapting this exhibition to accommodate sensory sensitivities.

To book or for more information, please contact Kirsten.petersen@hcc.govt.nz, call 07 838 6606.

For more details on events and exhibitions visit waikatomuseum.co.nz.

General admission

Adult - \$12

Child (4 to 14 years) - \$8

Child 0-3 years - Free

Concession* - \$10

Small Family (one adult and two children) - \$20

Large Family (two adults and up to four children) - \$40

*Concession applies to students, Friends of Waikato Museum and senior citizens. ID required.



Help or harm?



In this issue, we are featuring interventions – do they help or harm? Surrey Jackson provides us with an overview of fad interventions and reliable sources of evidence-based information on pages 8 and 9. We have developed a basic rating key to give you our at-a-glance opinion of the six interventions covered in this edition, shown on page 9. Each of the six interventions is coded with this key, with a summary of our views. We will provide reviews of additional intervention in future editions, and we are keen to hear your opinion and experiences of things you have tried.

With the new school year well under way, I hope all our students have settled into the rhythm of the new term. For families with students in secondary school, are you aware of the Special Assessment Conditions (SAC) for NCEA exams? SAC provide accommodations to ensure fair assessment of all students. A major concern is that far fewer students from low decile schools are applying for SAC compared with decile 10 schools.

In January, I had an opportunity to discuss this in an interview with Kathryn Ryan, Radio NZ *Nine to Noon*. To listen to this 13-minute interview go to our website: <http://www.altogetherautism.org.nz/2983/how-parents-can-get-exam-assistance-for-special-needs-students/>

One of the barriers for families applying for SAC is the \$400-\$900 cost of a professional report to support their application. The New Zealand Qualifications Authority (NZQA) and Ministry of Education have reviewed this requirement and are now emphasising a free assessment process, called alternative or school evidence. School evidence is information gathered by the school at no cost to the family or student. For a summary of key dates for SAC in 2016, see page 23.

Here in Hamilton, we have an exciting new collaboration with the Waikato Museum to create an autism-friendly opening of its latest installation, da Vinci Mechanics, as shown on the inside front cover. The museum space will be adapted to accommodate sensory sensitivities and museum staff are being upskilled for an autism audience.

Over the next few months, I will be travelling throughout New Zealand to attend our regional coordinators' network meetings. Our regional coordinators will contact you to let you know dates and locations for each of these meetings. We are also running Prism, our autism training for professionals, in various locations in the next few months; please see the back cover and our website for details.

We received an overwhelming response to our previous edition of this *Journal*, with nearly 200 new subscriptions. Thank you for your appreciation of this publication. Please complete our reader survey to help us improve it. The survey is found online at www.goo.gl/forms/QC8dNfsyxf or contact us if you would like us to post you a hard copy.

Hope to see you at the network meetings,

Catherine Trezona

National Manager, Altogether Autism

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WIN!!!

Complete our reader survey before March 31, 2016 and be in to win a \$100 Prezzie Card

Online survey:

www.goo.gl/forms/QC8dNfsyxf



Meet our new consultant psychologist

Altogether Autism is pleased to introduce its new consultant psychologist Jenny Gibbs who is taking over the reins from Tanya Breen.

Jenny is a clinical psychologist at Waikato Hospital's Child Development Centre and has worked there for 22 years. She has a strong interest in neurodevelopmental disorders, in particular autism spectrum disorder (ASD) and intellectual disability. She is also in her second term as representative of the Central North Island Allied Health and Nursing members on the Council of the Paediatric Society of New Zealand.

Before taking on the consultant psychologist role at Altogether Autism, she has been a member of the organisation's Professional Expert Group since 2008. She was also a member of a reference group which contributed to developing a training toolkit on ASD assessment, diagnosis and clinical management for paediatricians, psychiatrists, and psychologists. She was subsequently invited in 2011 and 2012 to co-present this training to these professional groups.

Jenny is excited about her new role with Altogether Autism and says she is impressed with how people on the spectrum get together to share lived experiences at the organisation's biennial conference. She would like to see a similar coming-together of New Zealand professionals who work with people with ASD.

One of Altogether Autism's strengths is its commitment to a strong evidence base and best practice, and Jenny hopes that by raising Altogether Autism's profile with professionals, it will become a clinical network for them.



Jenny lives in Hamilton with her partner of 30-something years and is mum to three adult children who she is "ridiculously proud of". None have given her grandchildren yet and she says she is trying not to pressure them too much. Her extended family is full of interesting and quirky characters, some of whom resemble the lovely people she meets in her working life.

In her spare time, Jenny enjoys reading, knitting, and has a recent passion for her vegetable garden.

Altogether Autism is extremely grateful to outgoing consultant clinical psychologist Tanya Breen. Tanya has played a pivotal role in the establishment of Altogether Autism and contributed her expertise, experience and creativity for the past 10 years. She has been a significant part of building Altogether Autism to the successful organisation it is today. We wish her all the best as she embarks upon her doctorate in health studies.



SAVE THE DATE

Altogether Autism 2017 Conference

July 19-20 2017
Holiday Inn Auckland Airport



PDA and the complexities of diagnosis

Pathological Demand Avoidance Syndrome (PDA) is thought by some to be an emerging syndrome. Its central feature is “an obsessive avoidance of the ordinary demands of everyday life” (Newson et al., 1993). The recent screening in New Zealand of the British documentary series *Born Naughty* has increased interest in PDA. In this article, **Altogether Autism** consultant clinical psychologist **JENNY GIBBS** considers PDA and reflects on the pros and cons of diagnostic labels in general.

PDA – what is it?

In 1980, developmental psychologist Elizabeth Newson presented to the British Paediatric Society the first 12 cases of what she believed to be a new and separate syndrome. She identified the key diagnostic criteria for a PDA diagnosis as an obsessive resistance to everyday demands and requests. Those with PDA will often use diversion, distraction, threats or extreme behaviour to regain control or to avoid a given task. This resistance may include the use of socially manipulative behaviour to avoid the demands, with sudden mood changes associated with a need to control the situation.

PDA – a rise in awareness

I am a clinical psychologist for whom a significant portion of my working life is the assessment of children under 16 where there is a question about whether they may have an autism spectrum diagnosis. The families of the children I see are often well informed about the emerging trends in assessment, diagnosis and intervention and I, like all clinicians, have on several occasions been introduced to new information by families. My challenge as a clinician is then to look critically at the evidence that supports the information. Is there a body of research behind it? Is this something that recognised experts in the autism field are discussing in the literature? Is this something that makes sense to experienced clinicians? Will this make a difference to our practice?

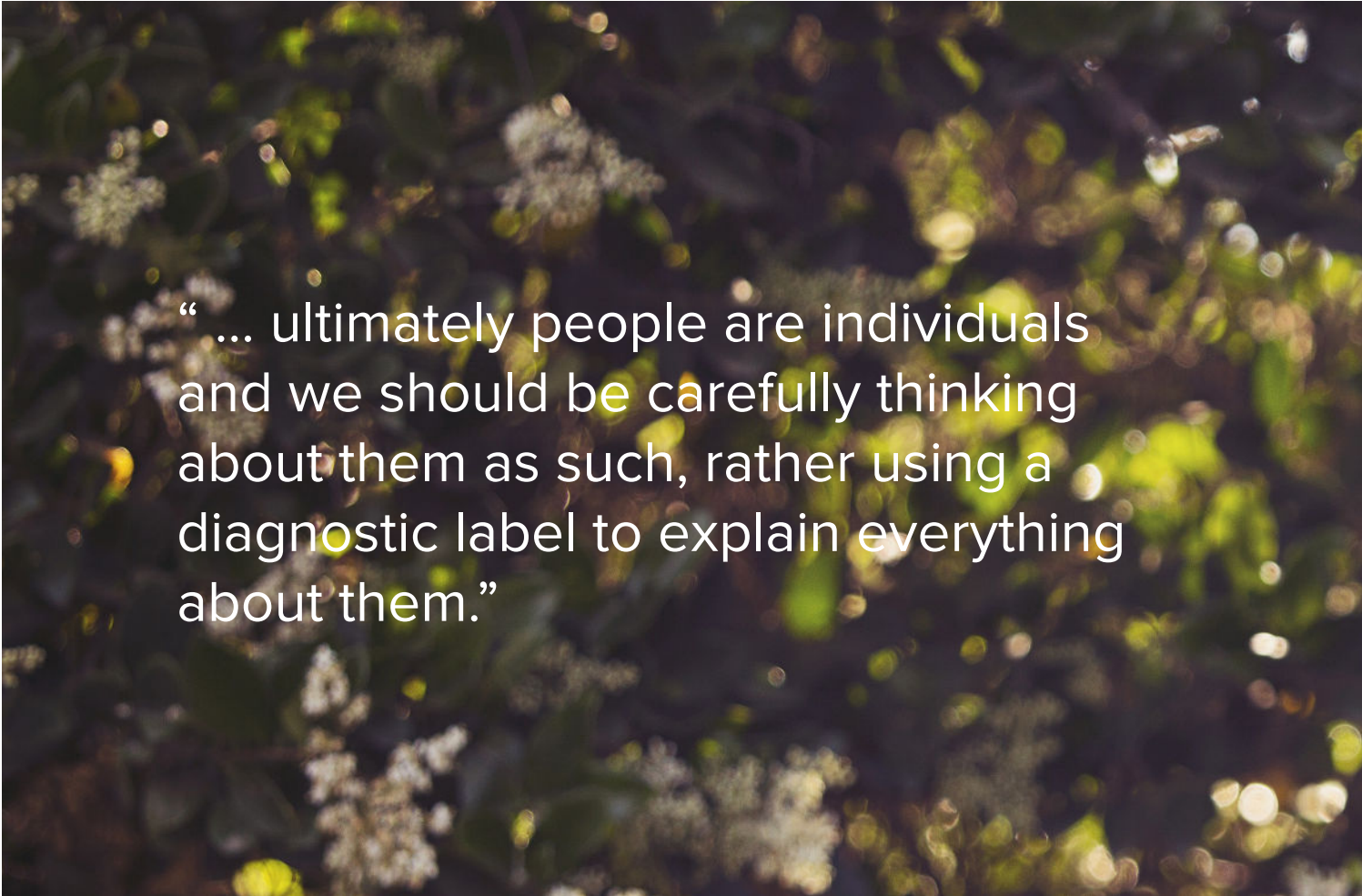
PDA is one such emerging trend. I first became aware of PDA via the family of a young man a couple of years ago. He was excluded from school, was highly oppositional and noncompliant, and the family were desperate for answers. Our clinical impression was that he met diagnostic criteria for autism spectrum disorder (ASD). The family were adamant that this was not the correct diagnosis and that he had PDA.

A literature search at the time found just two published articles in peer-reviewed journals, so we certainly could not be convinced by a large body of research. We were also cautious because the majority of the written material originated from one source; research carried out by Professor Elizabeth Newson from the Child Development Research Unit at Nottingham University. It was also clear that there were arguments amongst UK clinicians as to whether PDA was part of the autism spectrum, a different entity altogether, or simply a label for specific behaviours seen in children with a range of disorders (O’Nions et al., 2014).

Despite this, we could also see that the information was resonating with parents and professionals in the UK. A PDA society was established in 2014, and PDA is recognised as a diagnosis in the UK by the National Autistic Society, the Department of Education and the Autism Education Trust. I also recognised in the readings, a subgroup of children that I had seen over the years. These children were often referred with very challenging behaviour and may already have diagnoses such as Attention Deficit Hyperactivity Disorder (ADHD) and Oppositional Defiant Disorder (ODD). These were children who typically became highly anxious and oppositional with transition, change, requests and may avoid these with extreme behaviours. They were often excluded from educational settings, were involved with multiple services and had very stressed families. More recently, following screening in New Zealand of the British series *Born Naughty* there has been increased awareness of PDA, and clinicians around New Zealand are being asked questions about this by families.

Criteria for Pathological Demand Avoidance Syndrome (Christie, 2007):

- Passive in the first year of life
- Continues to resist and avoid ordinary demands of life – strategies may include distraction, giving excuses, delaying, arguing, withdrawal, challenging behaviour, and or violence
- Child has sufficient social understanding to be socially manipulative.
- Surface sociability but lack of deeper social understanding
- Sudden mood swings in response to pressure or expectations
- Comfortable in role play and pretend, taking on the roles of others
- Language differences, but not to the extent seen in Asperger’s
- Obsessive behaviour.



“... ultimately people are individuals and we should be carefully thinking about them as such, rather using a diagnostic label to explain everything about them.”

Despite the enthusiasm with which PDA is currently embraced and the knowledge that it describes children that I have seen in my practice, I continue to have reservations about PDA as a diagnosis. To some extent this reflects my reservation about diagnoses in general.

The complexities of diagnosis

All diagnoses for behavioural conditions (such as ASD, ADHD, and ODD) are essentially a consensus agreement (a “social construction”) amongst current experts about the cluster of behaviours, or symptoms, which must be seen in order for a diagnosis to be made. These consensus agreements change over time in response to current thinking and research, but are also impacted by societal influences. The ‘bible’ for diagnosticians – the Diagnostic and Statistical Manual of Mental Disorders (DSM) – has changed enormously since it was first published in 1952, and descriptions of autism and ADHD are now much broader, leading to a significant increase in diagnosis. In the latest version (DSM V), separate disorders including Asperger’s syndrome, autism, and the catch-all diagnosis of pervasive developmental disorder not otherwise specified (PDD-NOS), are now all included under the umbrella diagnosis of autism spectrum disorder. Undoubtedly there will be further changes to how autism spectrum conditions are described and it remains to be seen whether PDA is a useful and specific enough entity to become formally recognised in the future.

There is no specific “test” for behavioural conditions and diagnosis is influenced by the person doing the assessment. The outcome will vary depending on what kind of assessment tool

is used, the experience and training of the clinician, and who is asked for their perspective as there may be marked differences between the reports of the parents, teachers and clinicians. This is why people seek second opinions; different people can look at the same things in different ways. It is also why there needs to be some standardisation of assessment processes – but that is a whole other discussion.

The diagnosis of what are now described as spectrum conditions, as are most of the neurodevelopmental disorders, is inherently problematic. With any spectrum condition there is a cut-off point below which the person may have some but not enough of the symptoms to warrant diagnosis. There are many occasions where people may not meet diagnostic criteria for a condition but have many challenges that require support or intervention. In addition, many of the neurodevelopmental and psychiatric diagnoses have overlapping symptoms and clinicians can spend a lot of time considering whether it is one or other or both or all of these conditions.

The utility of seeking a PDA diagnosis

One of the main reasons for seeking a diagnosis is to access services. A diagnosis of PDA is problematic in New Zealand as it is not a recognised diagnosis and therefore does not provide access to any disability supports. It is important to note that in New Zealand a diagnosis is **not** required to access additional education resources. Access to special education services is on the basis of need, not diagnosis, although many children who access special education resources do in fact have a diagnosis. However, a diagnosis is necessary to be eligible for a needs



assessment for funded services through the Needs Assessment and Service Coordination services (NASC).

Access to services aside, diagnosis also promotes understanding about the condition, for families, educators, wider communities and the person themselves. A diagnosis can provide a great sense of relief for families; their child has something that can be named and understood and it is not their fault. There are also negatives about diagnoses; people may see the diagnosis, not the person, and sometimes diagnoses can in themselves be stigmatising.

Although it is not a recognised diagnosis and despite the ongoing disagreements as to its utility, PDA is clearly a description that has been helpful to some. In my practice, when I see children with this particular presentation I suggest that those working with the child and family might find the PDA information of interest. I do, however, feel somewhat uncomfortable doing so.

Using labels with caution

My concern is that diagnostic labels can result in a lazy approach to intervention. To say “this child has PDA, so the strategies for ASD won’t work” is simplistic and dangerous. Professionals in health, disability and education, should provide interventions based on a comprehensive assessment of an individual child’s strengths and difficulties.

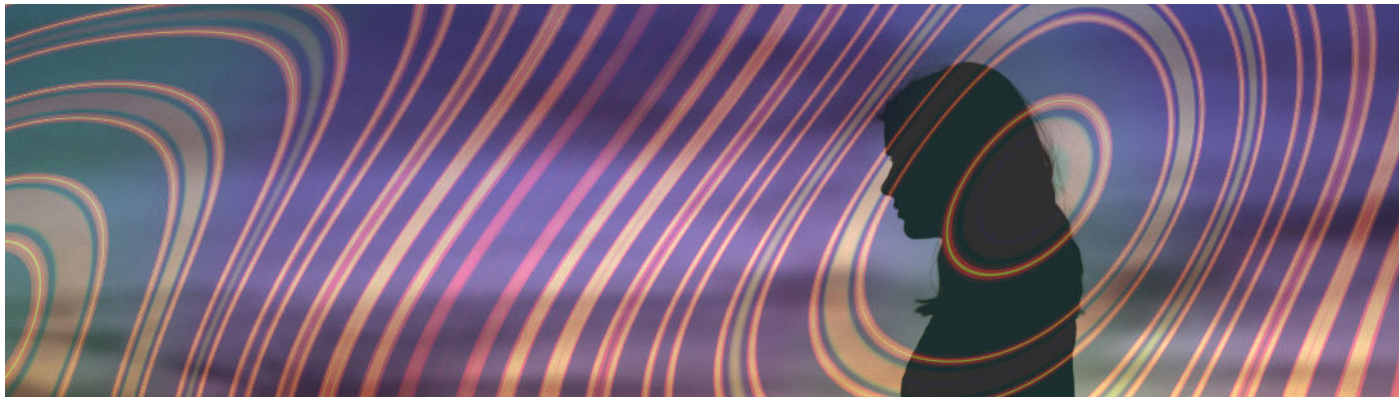
Intervention should not be a ‘cookbook’ response to a particular label. A diagnosis does not in itself tell us what intervention is required. We do not expect typical children to always respond the same way to the same strategies, so why would we expect that in a child whose development has followed a different trajectory?

Let’s remember that ultimately people are individuals and we should be carefully thinking about them as such, rather using a diagnostic label to explain everything about them.

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Help or Harm: Spotting fad interventions



By SURREY JACKSON

Often when you hear people talking about interventions for autism, you hear interventions must be 'evidence-based' spoken in the same sentence. This is for good reason. A Google search for 'autism' and 'intervention' gives over 34 million results.

Websites appear at the top of Google according to complex algorithms and the evidence base behind an intervention is unlikely to be part of the algorithm. This is unfortunate as many available interventions for autism are ineffective at best and harmful at worst and, sadly, ineffective interventions can become popular.

Choosing an intervention for autism is a complex and personal decision that needs to take into account the rights of the person receiving the intervention. The right to be fully informed and the right to receive services of an appropriate standard can both be directly related to the evidence base behind an intervention.

What is an intervention?

Research Autism defines interventions as “any kind of activity (such as a treatment, a therapy or the provision of a service that is designed to improve the quality of life for people on the autism spectrum)” (researchautism.net). This broad definition means that almost anything can be classed as an intervention, making it even more important that interventions are effective and safe.

What does evidence-based mean?

Many practitioners such as nurses, occupational therapists or psychologists are obligated to practice in an evidence-based way. For example, the American Psychological Association defines evidence-based practice as “the integration of the best available research with clinical expertise in the context of patient characteristics, culture and preferences” (apa.org). This means that psychologists should use particular methods for evaluating whether an intervention is working, take into account the current understanding of the disorder being treated, and use the best available research to help guide treatment decisions. Sometimes when a particular intervention has been studied extensively and

proven to be effective, people may say it is evidence-based. It is important to remember that although an intervention may have thorough research supporting it, the intervention should still be implemented as part of evidence-based practice to make sure it is effective.

What is a ‘fad’ intervention?

‘Fad’ interventions are interventions that are not based on science, and their effectiveness has not been researched. Some ‘fad’ interventions are pseudo-scientific – this means that the intervention seems to be based on real science but, when looked at closely, the research that has been done or the evidence presented does not follow the rules of actual science. Unfortunately there have been many times when a ‘fad’ treatment has become popular, despite there being no evidence base for it. In some cases this can be dangerous. For example, in 2013 the U.S. Food and Drug Administration released a warning against using Hyperbaric Oxygen Therapy as an off-label treatment for autism. They stated that the risks to using this treatment included mild injuries such as sinus pain, ear pressure, painful joints, or serious injuries such as paralysis or embolism.

Why does autism attract so many ‘fad’ interventions?

There are many reasons. For example, people with autism can often have advanced skills in some areas and ‘fad’ treatments can take credit for these skills developing. If a gain of skills happens to come along at a time when a ‘fad’ intervention has been in place, the intervention can be falsely given credit. Another reason is that research supports the fact that early intervention is important; this can lead to people feeling pressured to select and begin using an intervention even if the evidence behind it is only anecdotal.

How to protect against ‘fad’ interventions

You can protect yourself by knowing the warning signs. Making sure that you research interventions carefully, and obtain information from unbiased sources – and by asking questions to the service provider or person offering the intervention and checking that they can give satisfactory answers.

What are some warning signs for 'fad' interventions?

Be very sceptical of any interventions that:

- Offer a quick fix or a 'miracle' cure
- Cost a lot of money
- Use subjective evidence in their advertising such as testimonials and biographies as opposed to scientific papers
- Promise to treat a large range of conditions such as autism and migraines and ADHD, etc.
- Have emotionally appealing slogans and use catch phrases in their advertising.



What are some questions you can ask service providers?



1. What is the theory or rationale for this intervention?
2. Are there any scientific papers that say this intervention is effective?
3. How will we know if the intervention is working? What will the benefits be and what will they look like and how will they be measured?
4. Do you have any other anonymous data sets from other clients that show this intervention works?
5. How long will the intervention take? How will we know when it has worked, and when we can stop?
6. What are the possible side effects, and how will we measure and monitor these?
7. How difficult is it to implement the intervention correctly?

Where can I find evidence-based sources of information in New Zealand?

Altogether Autism www.altogetherautism.org.nz
The New Zealand Autism Spectrum Disorder Guideline
www.health.govt.nz/publication/new-zealand-autism-spectrum-disorder-guideline

Where can I find evidence-based sources of information internationally?

Association for Science in Autism Treatment www.asatonline.org
Research Autism www.researchautism.net
Raising Children Network www.raisingchildren.net.au

Surrey Jackson (BA MappPsy) is currently completing her PhD and is a registered intern psychologist. Her previous experience includes five years' tutoring and teaching behaviour analysis and psychology at the University of Waikato, and she has worked previously as a researcher for Altogether Autism.

Help or Harm - intervention rating key

Altogether Autism has developed this rating key as a quick reference guide to our views on the interventions covered in this article.



The evidence suggests this intervention is effective, and is backed up by good quality studies.



There is no research on this topic, or the evidence suggests this intervention is not effective and may be harmful.



The evidence is inconclusive at current or it is still emerging. Watch this space!



This intervention is considered dangerous!



Are robots helping children with autism?



By **REBECCA ARMSTRONG**

New Zealand children are familiar with Milo as a chocolate milk drink, but now there is a new Milo on the scene.

RoboKind, a Texas-based robotics company is introducing Milo the Robot to children with autism. They claim Milo can help children on the spectrum manage better with social interactions and communication. In this article, we meet Milo and see what the research says.

What is Milo?

Milo is a humanoid robot, with a human-like face, spiky hair and a child-like, friendly voice. He has a video screen on his chest that shows symbols. He also has sensors, cameras and facial recognition software that record a student's responses. RoboKind advertises Milo as a learning tool for children with autism for use by educators, therapists and parents. They claim that Milo can help children understand the meanings of emotions, to express empathy, to self motivate and to demonstrate appropriate social behaviour and responses. It is also suggested that using a robot in therapy may encourage engagement with the therapist. Milo costs US\$5,000 and comes with an autism-specific curriculum.

Robots4Autism curriculum

Robots4Autism is a research-based curriculum designed for children aged 5-14 on the autism spectrum. Both the instructor and student have a tablet which uses social stories and visual modelling, which have proven success for people with autism. Milo models a range of social situations and deconstructs them into plain language. The curriculum includes calm down

techniques, making conversation, playdates and birthday parties. Milo also gives children practise in interpreting emotions and facial expressions, and in how to be a good friend for example playing together and sharing toys. Throughout the sessions Milo is actively monitoring the student, measuring the amount of eye contact from children, the speed of their responses, and whether to move forward or to repeat a module

What Robots4Autism is saying about Milo

- Milo helps autistic children opening up and engage more effectively than with human teachers.
- Therapists working with Milo have a 70% better engagement from the child compared to the therapist working without Milo. Engagement was measured by increased in eye contact, body language and friendliness.
- Milo helps children act more appropriately in social situations, to self-motivate and self regulate and can apply this into other social situations. .
- RoboKind found that Milo is best suited to work with children who have the following skills: picture symbol recognition, ability to answer yes/no questions, ability to understand cause and effect and the ability to use a tablet to communicate (Kroiss, Sonogo & Rollins, 2014).

Why do researchers think Milo might be helpful for children with autism?

- Children with autism exhibit strengths in understanding the physical world and relative weaknesses in understanding the social world. (*Klin, Lin, Gorrindo, Ramsay & Jones, 2009*)
- Children living with autism are generally more responsive to feedback, even social feedback, when administered by technology rather than a human. (*Ozonoff, 1995*)

- Children on the spectrum are more inherently interested in treatment when it involves electronic or robotic components. (Robins, Dautenhahn & Debowski, 2006)
- The use of robots uses techniques that have a history of success such as social stories, *chaining, modelling, and using special interests (as cited in Diehl et al., 2012).

But does Milo help?

Apart from RoboKind and Robots4Autism, research is limited. Milo and other robots such as Zeno, his older 'brother', are still very new. There is some anecdotal evidence in the form of case studies. But we don't yet know whether the skills learned with Milo are generalised by the child and used in other situations. Some research has looked at the effectiveness of different types of robots (i.e. humanoid vs non-humanoid). Peca et al. (2014) found a high preference in children with autism for robots that had a human-like design with exaggerated facial features, like Milo.

However, there is little emphasis on the best ways to integrate a robot into therapy sessions. Diehl et al. (2012) reviewed the literature on the clinical use of robots for individuals with autism. They provide a comprehensive overview of peer reviewed studies that fit into four broad categories; responses to robots or robot-like characteristics, eliciting behaviour, modelling, teaching or practising skills and providing feedback and encouragement. In each category, the results were varied and inconclusive.

Joint attention

Of all the trends currently researched in child-robot interactions, joint attention is the area with the clearest results to date. Joint attention is where two or more people use gestures or gaze to share attention with respect to interesting object and events, and is often difficult for people on the spectrum. In 2013, Kim and colleagues conducted one of the largest demonstrations

of social interaction between children with autism and robots when they examined the social behaviours of 24 4 to 12-year-old children with autism (Kim et al., 2013). In this study, the children experienced three different joint attention interactions with an adult partner. The interaction partner was an adult human, a touchscreen computer game or a social dinosaur robot. The results showed that children spoke more in general and directed more speech to the adult partner when the interaction partner was a robot compared to a human or computer game. This study provides the largest demonstration of social-robot interaction in children with autism to date and shows promising results. Ricks and Colton (2010) also looked at joint attention when they looked at a range of trends in robot-assisted therapies.

In addition to joint attention, they also investigated diagnosis, self-initiated interactions, turn-taking activities, imitation, and emotion recognition. They concluded that joint attention interactions have the greatest potential for success, which is good news for Milo, as this is the way he is currently used.

Our views - Help or Harm?



Based on the research, we conclude that Milo could be an effective learning tool for children with autism, especially where the aim is to develop joint attention. However because robots are so new, the research on the use of interactive robots for people with autism is in its infancy. Our view is that Milo and other robots should be considered as potentially useful, but more research is needed before we can confirm this as an evidence-based intervention.

**Chaining is a method for teaching new skills which involves breaking down a task into smaller, achievable pieces. Each unit is mastered before progressing to the next. It essentially links lots of small steps together to form a more complex task.*

Rebecca Armstrong (BSocSc, MAppPsy Behaviour Analysis) is a researcher for Altogether Autism and Parent to Parent.

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No evidence Yasko Protocol works

THE YASKO PROTOCOL: Dr Amy Yasko claims stress, toxins and genetics interact to cause autism. The Yasko protocol generally starts with a genetic test to identify potential mutations that may impact the methylation* cycle. Urine amino acid testing is done twice a month to monitor biomarkers of detoxification. Dr Yasko then recommends a comprehensive intake of supplements and a special diet. She also recommends foods to avoid to promote better health.

Nutrigenomic testing

Nutrigenomic testing is where analysis of a person's genes is used to develop a personalised regimen of specific nutrients to help that person's genes function at optimal efficiency (Science Based Medicine, 2013). The idea of studying genes to personalise therapy is not of itself problematic. Genetic analysis is already used to diagnose certain diseases and to target chemotherapy (Science Based Medicine, 2013). Recently genetic analysis has become more cost-effective and this has led to an increase in its use as part of health screening. However, no information about the use of nutrigenomic testing and its benefits / risks for treating autism has been found.

Evidence on the Yasko Protocol

We have researched the Yasko Protocol, considering both where it does appear in the literature and where it does not. One of the tests for a well reputed treatment is to see if other researchers in the field make reference to it, especially as Dr Yasko is an experienced microbiologist. However, no publications relating to her protocol can be found. Since training and working as a scientist in well-known institutions such as Yale Medical Centre, she gained two doctorates at the Clayton College of Natural Health. This college closed suddenly in 2010, and those listing qualifications from this college can be identified as someone not to consult for advice, according to Stephen Barrett of Quackwatch, due to dubious claims made by the college. We also found a number of newspaper articles highlighting the same lack of evidence for the Yasko Protocol as we found.

A search of the major scientific literature database PubMed, in 2010 did not yield any hits for "Yasko" or "Amy Yasko" (Willingham & Wombles, 2010). This is not surprising as Dr Yasko states in her website that "when I moved from academic

research to biotechnology to integrative healthcare, I changed the way I shared information – from scientific articles in peer-reviewed journals – to books, internet, conferences, videos, and articles" (Dr Amy Yasko, 2014). This move away from peer-reviewed publications to more informal formats makes it difficult to establish the scientific evidence for the Yasko Protocol.

Our Views - Help or Harm?



We requested input from our Professional Experts Group, which has expressed concerns regarding this protocol and its associated procedures, due to the lack of evidence in published peer-reviewed literature. The Yasko Protocol is not an internationally recognised treatment methodology. The cost of the treatment is a further concern (US\$495 + Shipping), especially as there is no scientifically-validated evidence that it works.

– by the Altogether Autism research team

*Methylation

Methylation in biological systems (including people) is a complex process and can be involved in the regulation of gene expression, the modification of heavy metals, the regulation of protein functions and RNA processing. Methylation is highly variable across cell types and varies between individuals, so it is difficult to know what 'normal' methylation looks like. Dr. Amy Yasko defines the Methylation Cycle as a biochemical pathway by which methyl groups are added to DNA resulting in changes to the function of the DNA.

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Questioning the use of coreboards



By TEGAN ANDREWS

Coreboards, a clipboard with pictures, symbols and words, are being increasingly used with people with autism. Is this communication tool an effective one?

What are coreboards?

Coreboards are primarily used to help people with limited spoken communication. The key to understanding coreboards lies in the name – a grid of ‘core’ words are represented by pictures and symbols on a ‘board’. The core vocabulary is made up of familiar words the person uses on a regular basis. They can be tailored to the individual’s needs and activities. Coreboards are an example of an Augmentative and Alternative Communication (AAC) strategy. In this context, ‘augmentative’ simply means in addition to natural speech, and ‘alternative’ means instead of spoken language

How do coreboards work?

To use the coreboard, the person points to the pictures or symbols to communicate with another person. They are similar to Pragmatic Organisation Dynamic Display (PODD) books, both of which are based on providing a set of core vocabulary in pictures so the user can develop expressive language independently. For example, a teacher could point to a series of symbols to give an instruction like “keep working quietly” and the student in this scenario could point to a series of symbols indicating “I need help” or “I have finished, can I go play?” Both coreboards and PODD books are set out specifically for easy access to frequent words reducing the time it takes to make multi-symbol statements

What’s the difference between coreboards and the Picture Exchange Communication System (PECS)?

One of the key differences between coreboards and the more widely used PECS is that PECS is explicitly taught through a series of six phases, where as coreboards do not seem to have this structured training. The six phases of PECS are teaching the physical exchange of a card for an item, encouraging spontaneous requests, teaching to tell the difference between symbols, putting the symbols into a sentence, responding to the question “What do you want?”. Phase six focuses on commenting such as “I see a bird.” PECS symbols are mostly nouns and adjectives. Coreboards begin with mostly nouns, starting with those most familiar to the person with autism. As the person learns new words and the vocabulary on the coreboards is extended, the words become harder to teach as they are more abstract. It is thought, but not proven, that this gives the person the ability to express a wider range of statements compared with PECS.

Our Views - Help or Harm?



Currently coreboards are being used in some schools in New Zealand. Staff believe that coreboards are useful to give instruction or direction, explain tasks, assist in understanding rules and expectations, and develop understanding of concepts. Speech and language therapists also report the successful use of coreboards with some families. However, there is no research into the effectiveness of coreboards. This intervention would be safe and inexpensive to implement but it may not be as effective as other communication systems such as PECS which have a strong evidence base.

The coreboard is used to teach core vocabulary, which is said to support the child in:

- Gaining a true understanding of word meanings
- Increasing the diversity and generalisation of words, and
- Achieving independent communication skills.



Fair evidence for sleep hormone



By TEGAN ANDREWS

You may be aware that sleep problems are common in people with autism. Between 40-60% of children living with autism experience sleep disturbance – difficulty falling asleep, frequent night waking and early waking. Sleeping difficulties are important to address as they impact on learning, behaviour

and can add to family stress. One intervention for sleep disturbances is melatonin. This article looks at the safety and effectiveness of using melatonin for children with autism.

What is melatonin?

Melatonin is a naturally-produced hormone which prepares the body for the onset of darkness and is released throughout the sleep process. It can also be taken as a supplement to help with sleep disturbances. It comes in liquid, capsules and tablets. In New Zealand you can only obtain melatonin supplements with a prescription

Is melatonin safe?

Only the short-term safety of melatonin has been established. A review of the research showed that some children experience side effects. Out of 215 children across 12 studies, two children experienced tiredness, two had daytime sleepiness, one reported foggy, one had dizziness, one experienced increased bedwetting, one experienced headaches and one reported diarrhea (Guenole et al., 2011). In summary, there are some side effects with short-term use, but they are not common. No research has been located that looked into long-term use.

Types of sleep issues:

- Early morning waking
- Delayed sleep onset (difficulty falling asleep)
- Frequent night waking
- Insufficient total sleep time.

Is melatonin effective?

The research indicates that melatonin may be effective for some sleep disturbances in children with autism. One study used the medical records of 107 children diagnosed with autism who reported difficulty getting to sleep, waking during the night, early waking and combinations of these (Anderson et al., 2008). The children were aged 2-18 years and had been recommended to take melatonin by their doctor. The follow-up notes indicated that melatonin was effective for 85% of the children, meaning sleep concerns improved to some degree. There was no information regarding when follow-ups occurred after melatonin was introduced. This study used self-report as the only outcome measure, which has limited reliability.

A further study in 2011 assessed the effectiveness of melatonin when compared to a placebo in a randomised double-blind cross-over trial*. Participants were 22 children (aged 3-16 years) with an autism diagnosis who had sleep issues – either excessive time getting to sleep, excessive night waking or reduced total sleep time (Wright et al., 2011). These issues are not further defined as there was no clear definition as to what an “excessive time” is to get to sleep. On average, when children were given the melatonin they were able to get to sleep faster (an average of 51.7 minutes) and have a longer sleep (by an average of 52.3 minutes).

Another study just looked at whether melatonin decreased the time it took for 24 children to get to sleep. Children were aged 3-10 years with autism whose parents said on three or more nights a week there was a delay in getting to sleep by 30 minutes or longer. Children were required to wear a watch-like device to record motion, which measured when the child was asleep, and parents had to fill in several questionnaires. They found that melatonin was effective in reducing the time it took to get sleep (Malow et al., 2012).

Melatonin is only recommended where behavioural interventions have been implemented but not successful in resolving sleep issues. Behavioural interventions include choosing an appropriate bedtime, establishing a consistent routine in regards to bedtime and wake time, and minimising television and computer/video games before bed. Noise, light and temperature should be controlled where possible and further accommodations may be needed for children with hypersensitivity to bed clothes and blankets (Cortesi et al., 2010).



Our views - Help or Harm?



Overall, there is fair evidence for melatonin as an effective treatment for sleep issues in children with autism. The research in this area is still relatively new and the effectiveness and safety of melatonin is still being researched. The NZ ASD Guideline has the following recommendation regarding melatonin use: 'Melatonin may be useful for improving sleep in children with ASD who have impaired sleep' (Recommendation 4.4.7, Ministries of Health and Education, 2008). They have graded this as Grade B (representing 'fair evidence'), indicating studies are mostly valid, but there are some concerns relating to various factors in the evidence (volume, consistency, applicability and or clinical relevance) (Ministries of Health and Education, 2008; New Zealand Guidelines Group, 2011).

*A randomised double-blind cross-over study is a study where participants are randomly assigned to groups, where the researcher, participants and their family are blind (unaware) to what condition they are in and switch conditions after a pre-determined time period (so they experience both melatonin and the placebo). It is considered one of the best scientific methods and is commonly used in medical trials.

Tegan Andrews (BSocSc, MAppPsy Behaviour Analysis) is a researcher for Altogether Autism and Parent to Parent, currently studying for her PhD in Psychology.

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Do weighted blankets improve sleep for children with autism?



By TEGAN ANDREWS

What is a weighted blanket?

A weighted blanket is a blanket which is made heavy by sewing metal or plastic, or grain into quilted layers. It is thought that this gentle, deep pressure helps with sensory integration and reduces arousal and stress, thereby

improving sleep. Weighted blankets cost between NZ\$300-400 and advocates consider them a relatively cheap, non-drug intervention for improving sleep issues in children with autism.

Are weighted blankets effective?

Surprisingly, given the popularity of weighted blankets, there is very little published research. In 2014, Paul Gringras, Professor of children's sleep medicine and neurodisability at Evelina London Children's Hospital, led a team in conducting a randomised controlled trial (RCT)* to see if weighted blankets helped children with autism sleep. Sixty three children with autism and sleep problems aged 5-16 years were given either a weighted blanket or a non-weighted but otherwise identical blanket for two weeks. The researchers then switched the blankets for a further two weeks so that all children experienced sleeping under both types of blankets. Parents completed sleep diaries and the children wore a wrist-watch that measured the quality and duration of their sleep. The results showed that the use of the weighted blanket did not help the children sleep for longer periods of time, fall asleep faster or wake less often. However, both the children and parents preferred the weighted blanket and thought it helped the children sleep better and make them calmer (Gringras et al., 2014).

In New Zealand, a masters' research project completed by Jane Charleson at the University of Canterbury looked at the effectiveness of weighted blankets for sleep issues in five children aged 7-13 years with autism. The sleep problems experienced by these children ranged from early morning waking, delayed sleep onset, total sleep duration, night-time waking and co-sleeping. Four of the five participants were taking melatonin for their sleep disturbances. Of the five participants, one refused to use the blanket and the other four had no significant improvements in their sleep (Charleson, 2014).

Are weighted blankets safe?

Although the research has not yet proven that weighted blankets help, if children and parents like them, is there any harm in using them? The answer is unfortunately yes. In 2008, Gabriel Poirier, a young boy with autism died while using a weighted blanket in Quebec. Gabriel was rolled in a heavy buckwheat-stuffed blanket by school staff, with only the tips of his ears showing as a form of discipline when he wouldn't keep quiet. The staff member set a timer for 20 minutes but when they returned to check on him, Gabriel was found unconscious and unresponsive and later died.

Following this tragic event, the Coroner Rudel-Tessier of Québec recommends;

"Because the therapeutic value of weight blankets does not seem to be proven scientifically, and because of the fact that they pose a risk for children's lives, we could be tempted to prohibit their use altogether. However, I believe that it is possible to manage usage in a strict manner in order to minimize the danger. I believe that certain ground rules must be respected by those who wish to use this sensory pressure technique, namely:

"- A health professional's advice must be obtained to ensure that the use of the blanket is suitable for the child.

- The weight of the blanket must be in proportion to the child's physique and weight.

- The child's head must never be, or be able to be, covered by the blanket

- Vital signs should always be observable

- The child must never be rolled in a blanket (unless a therapist is constantly at his or her side)

- A child must never be left unsupervised

- The child must be able to easily slip out of the blanket if he or she wishes to do so (it is not a confinement)

- The child must express his or her consent to this, even if it is not verbal."

– cited from Autism Society Canada, 2008



What about using weighted blankets while awake?

There are anecdotal reports suggesting that weighted items such as blankets and vests can be safely and successfully used to help children with autism calm and focus when used for short periods while the child is awake. It is possible that weighted blankets may relax some children while they are awake. But the results of a small number of studies looking at weighted items as a way to help children calm or concentrate show no or mixed benefits. If weighted blankets are used, the safety recommendations need to be followed, whether the child is awake or asleep.

Our views - Help or Harm?



Research into weighted blankets as a sleep aid for children with autism has not shown them to be more effective than normal weight blankets. The death of a child through the inappropriate use of a weighted blanket has led to safety recommendations for using weighted items. There are anecdotal reports of weighted items helping children to relax when awake. However, we would not recommend weighted blankets to help children with autism sleep, as they have not yet been proven to be effective or safe.

*Randomised Controlled Trial (RCT)

A study where people are allocated at random (by chance) to receive one of several clinical interventions. RCT are considered to be one of the simplest yet most powerful tools of research.

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Warning over 'miracle cure'



By GLENN LAMBERT-VICKERS

Miracle Mineral Solution (MMS) has been marketed by Miracle Mineral Trust in New Zealand as a supposed autism 'cure'. MMS is also claimed to cure many diseases, including cancer, hepatitis and HIV. Health authorities state there is no basis to these claims and ingesting the solution can cause serious health risks and is potentially fatal.

MMS consists of sodium chlorite and hydrochloric acid which becomes chlorine dioxide, or bleach, when diluted with lemon juice. The chlorine dioxide solution is then taken orally or by enema. Claims made on the Miracle Mineral Trust website use pseudoscience techniques to suggest evidence for benefits the solution and are designed to mislead consumers into buying the product as a miracle cure.

Health authorities state there is no evidence to back claims that MMS is a successful intervention for any condition and

that ingesting bleach is harmful. The US Food and Drug Administration states high oral doses of this bleach, such as those recommended in the labelling, can cause nausea, vomiting, diarrhoea, and symptoms of severe dehydration.

In May 2015 Louis Daniel Smith was convicted by a federal jury in Washington for selling industrial bleach, marketed as MMS, as a cure for a range of conditions. Smith provided instructions with the product that nausea, vomiting and diarrhoea were all indications the miracle cure was working. A maximum sentence of 34 years was imposed. The BBC exposed a secret conference run by Leon Edwards in Surrey, England to promote MMS as an autism 'cure' in June 2015. Edwards suggested autism could be purged by the solution, a claim with no scientific basis.

Our Views - Help or Harm?



If you who have bought MMS we strongly advise you to stop taking it and to throw it away. If you have experienced any negative health impacts as a result of taking MMS please seek the advice of a qualified healthcare professional.

News

New research looks at diagnoses criteria

Recent research from Emma Goodall and Matthew Bennett has raised concerns around the reduction in autism diagnoses under the DSM-5. Those most likely to no longer meet the diagnostic criteria for autism were those with a diagnosis of PDD-NOS, followed by those with Asperger syndrome, and lastly by people with autism.

The research involved a review of six studies which looked at autism diagnoses in light of changes to the DSM-V in 2013. The study found that these changes to the diagnostic criteria for autism spectrum disorder (ASD) in 2013 has meant that people who previously met the criteria under version four (DSM-IV) or text revised version four (DSM-IV-TR) may not meet the criteria under the current DSM-V. While those with a diagnosis are unaffected by this change, people seeking a diagnosis or requiring one in the future may experience the stricter criteria. A diagnosis is often the key to accessing funded supports and services.

In Emma's words: "Until such time as we can support people on the basis that everyone has strengths and everyone has support needs, issues such as the eligibility criteria for an autism spectrum diagnosis will remain highly problematic and subjective. The current need to be clinically significantly impaired is in itself an impediment to seeing autistics as able to succeed in life."

Here at Altogether Autism we would like to congratulate Emma and her colleague Matthew on this interesting and important piece of research!



Dr Emma Goodall

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It's all about the Attitude

Two young artists who have Asperger's syndrome – Salem Foxx and Yaniv Janson – are showing the world that there's no limit to their talent after being honoured at the 2015 Attitude Awards in Auckland in December.



By KATE DORAN

Kapiti Coast dancer, Salem Foxx, won the Artistic Achievement category for dedication and passion for dance – including ballet, jazz, tap, lyrical and even acrobatic dance.

Salem, 16, has achieved outstanding marks in his dance exams, including a 100% score for his New Zealand Association of Modern Dance (NZAMD) Level 4 Contemporary exam. He has danced with the Royal New Zealand Ballet, and in many productions, and also assists in teaching Grade One and Two ballet classes.

"Just being a finalist for the Attitude Awards is a great experience," says Salem. "You get treated like a rock star and get to meet such amazing people. Being a winner was so unexpected and is such an honour especially when I was up against two fantastic artists.



Salem Foxx with Altogether Autism National Manager Catherine Trezona at the Attitude Awards

"Winning the Artistic Achievement Award means a lot, especially as it is for doing something that I love. It is nice to have something positive about people with Asperger's instead of all the negative things that have been in the media lately. I want people to know that having Asperger's, for me, is a gift; without it I would not have the passion and my own quirky way of looking at dance and movement."

Salem has just spent the summer in Sydney at the National Boys' Ballet Summer School to focus on ballet, contemporary and jazz dancing.

"I had a fantastic time at the Boys' Ballet Summer School in Sydney," he says. "This was my second time and I got to catch up with friends from last year and made new ones too. It is so different being in an all-male environment for dance when, more often than not, I am the only male at dance classes and even at competitions.

"I learnt so much, as the Australian style of teaching is quite different to what we have in New Zealand, especially for boys. I had such a great time, I wish it went for longer."

Salem also writes a blog ([balletboyz](http://balletboyz.com)) that showcases his training and routines to other young dancers.

Hamilton-based artist Yaniv Janson, was a finalist in the same Artistic Achievement category at the Awards. Diagnosed with Asperger's as a toddler, Yaniv produces vibrant paintings that have been turning heads in New Zealand and overseas. Yaniv, 23, became interested in art at high school, where he developed his signature technique of mixing acrylic paints and water straight on the canvas.

At 17 he was the youngest artist to be a finalist in the Trust Waikato National Contemporary Arts Award and the Wallace Trust Arts Award.

Yaniv's work has also received significant international attention. He was the first New Zealander to be invited to join the Paris-based Eg'Art organisation, which works to raise the recognition of artists with disabilities. His paintings have now been exhibited in Israel, Canada and California.

"It was great to be a finalist at the Attitude Awards," says Yaniv. "I got to meet lots of interesting people, for instance Simon Dallow. I was stoked that the painting I donated to the auction raised \$3000 for KidsCan and that Olivier Lacoua, the general manager at Comfort Quality Wellington Hotel who bought it, will have it exhibited in this hotel!"

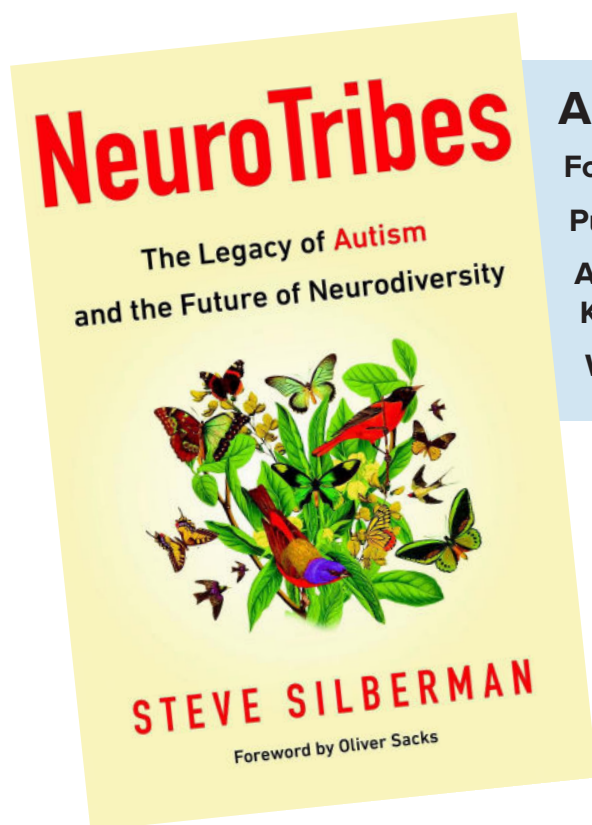
Yaniv's website, which includes examples of his art, is at www.yanivjanson.com.



Artist Yaniv Janson. View Yaniv's work at www.yanivjanson.com

NeuroTribes: The Legacy of Autism and the Future of Neurodiversity

Reviewed by JOHN GREALLY



Author: Steve Silberman

Foreword: Oliver Sacks

Published August 25, 2015 by Eureka Books

Available at Amazon.com:

Kindle US\$9.90, Hardcover US\$16.59+p&p

Winner of the 2015 Samuel Johnson Prize for non-fiction.

"Ambitious, meticulous and large-hearted history ... NeuroTribes is beautifully told, humanizing, important."

— **The New York Times Book Review**

"Mr. Silberman has surely written the definitive book about [autism's] past."

— **The Economist**

"A comprehensive history of the science and culture surrounding autism studies ... an essential resource."

— **Nature magazine**

The NeuroTribes revolution changes everything! This book is guaranteed to intimately and extensively change, reorient and inform any reader about autism and autistics in their lives.

Steve Silberman's autism best-seller is rapidly changing so many people's thinking in autism and autistic communities, simply because it brings together such a welter of new information to upset and overturn so much of what we all thought as settled about autism and autistics.

It is a very meaty read – 544 pages – consisting much of new and exciting documents, crucial overlooked research, clear cases of serious misinformation, and a thrilling peek into how the Europeans with Dr Hans Asperger went one way:

– psychology, difference, diversity, accommodation, acceptance and the Americans with Dr Leo Kanner quite another way:
– psychiatry, psychotherapy, disorder, experimentation, awareness.

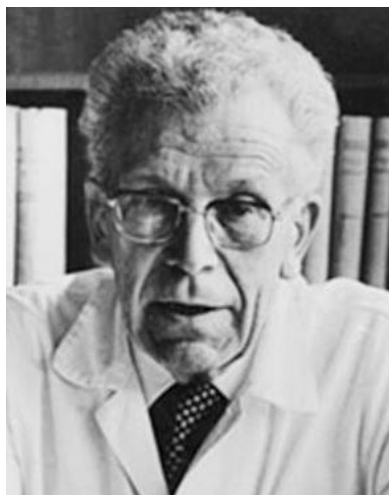
The implications have for many decades been huge for parents, professionals, policy makers – but mostly for the harshly impacted lives of autistics themselves. Steve Silberman, a loved and loving neophyte of the late, great Oliver Sacks, was a writer for favourite nerd techie magazine *Wired*, and his

coverage of autism at first was not that positive or well-received as he stumbled into it all haphazardly, inspecting mainly the manifestation of autism in Silicon Valley.

But the subject had an uncanny way of repeatedly cropping up for Steve and, before long, he set out to exhaustively study the subject from his non-autistic perspective using his considerable research skills, his amazing background, and many accesses to information not touched on before.

What resulted is not just THE definitive history of autism but many helpful clues to a way ahead that don't seek to file autism in the "too hard" basket, or leave it greatly misunderstood, wrongly approached.

Silberman uncovered a critical link (Dr Frankl) that showed the very independent work of both Kanner and Asperger were neither independent nor simultaneous discoveries at all; that the impact of the respective disciplines of Kanner (psychiatry) and Asperger (psychology) were to have a momentous impact on all



"It seems that for success in science or art, a dash of autism is essential."

— Hans Asperger —

that has since followed. This is what makes the book read – in part – more like a murder mystery unravelling than the usual history genre fare.

Here in New Zealand, a much gentler insightful approach ("work with their strengths", "different but equal", "accommodate and allow for") is followed as a result of powerful links with Hans Asperger, the UK, Australia, Attwood, Larkey, Wing, Frith, Baron-Cohen and the National Autistic Society, than a hard-nosed and rather desperate approach followed by Autism Speaks and ABA proponents emanating from the USA.

Silberman's discovery of the link between Kanner and Asperger's seminal work gives a certain precedence to the work of Hans Asperger now, reviving his reputation at a time when the DSM has set aside more than just the word 'Asperger's', but also quite a few on the spectrum also, by redefining autism as demanding some very limited psychiatric understanding of a 'daily struggle' before diagnosis becomes possible now.

Asperger's view of autism was vast, broad, 'a continuum,' or as we would now say 'the spectrum'. It allowed for a breath-taking range of strengths and impairments. Asperger was aware the condition was not rare... once you went looking for it, it came looking for you. Kanner, in keeping with his special interest for very rare discoveries, chose to limit autism to be a rare form of childhood 'psychosis' and, later on was pressured by Freudian psychoanalytic associates to adopt some wildly wrong views as to the cause - such as bad parenting and "refrigerator mothers". This still sticks with some of the public, this still hurts parents today. Even when spoken aloud.

And that is not the only reason why this book is excellent news for parents and anyone journeying with autistics well away from all those sad legacy side-streets that led to nothing but grief and self-blame. It wasn't just parents who were stigmatised either as a result. Children were also. Adults were overlooked ... no room for over 18s to have some 'childhood psychosis'. Abandonment by government and agencies, for the most part, is a searing theme parents well know of.

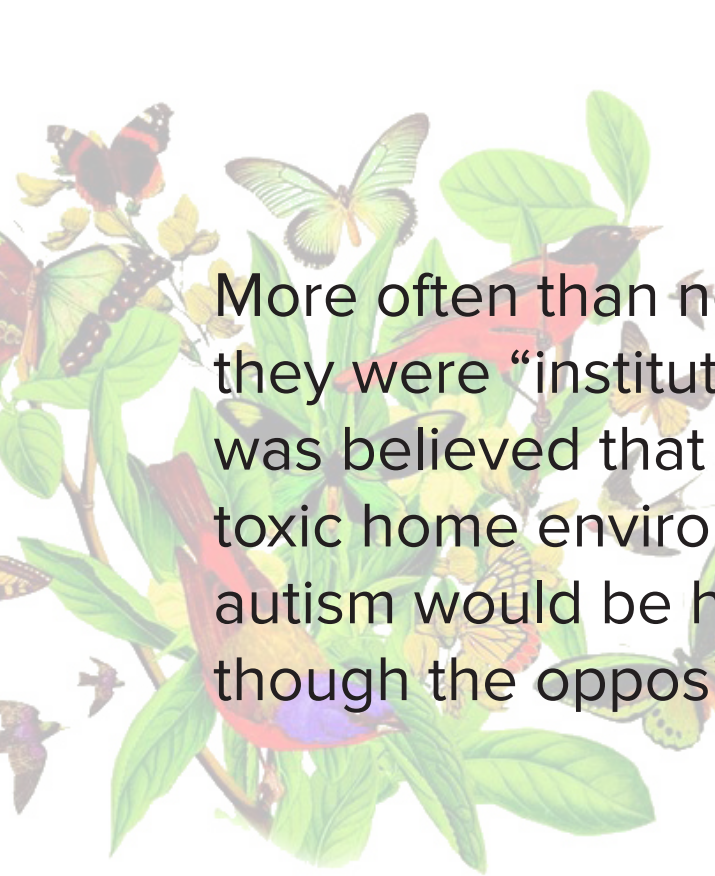
Even to this day, most of the counting of how many autistics there are is based on Kanner-led/Kanner-focused USA statistics from its Centre for Disease Control (CDC) ... not from the UK where they have sensed how common autism can be much earlier, and where talk of 'epidemics', 'tsunami', 'increase' are muted at most. Even autism being under the aegis of an

organisation with 'Disease' in its name like the CDC, or 'Mental Health' like the DSM (*The Diagnostic and Statistical Manual of Mental Disorders*) is an impact of the Kanner association once looked at historically. Dominating stuff. And not for the good of millions either.

Canvassed in this book are essential questions such as: Where did this all begin? Why the different approaches? Why do countries approach autism so differently (France and Argentina - ugh, it's appalling!)? Why so little progress over the years? Why is there so little research actually about care of autistics and how they are faring? Why does it all matter so much? Why do autistic adults get ignored or silenced so often? What misfortunes have befallen autistics and those who care for them? Where was autism miscategorised as a medical, and not largely a social issue? Why does a change in perspective make such a world of difference to an autistic child or adult? Where do we go from here?

This book also puts what so many autistics have said over the years into non-autistic language, explained in a comprehensible way that the angst of the autistic advocate might not convey so well or acceptably. It references beyond much doubt what others might have had difficulties accepting without such a level of deep scholarship. It removes the distraction of all autistic detail and presents a whole big picture that is consistent, contextualised, compelling.





More often than not, said Silberman, they were “institutionalized because it was believed that taking them out of the toxic home environment that created the autism would be healthy for them, even though the opposite was true.”

Perhaps only Professor Lorna Wing’s translation and commentary of Hans Asperger’s 1944 paper and the inestimable compendium by Professor Tony Attwood *The Complete Guide to Asperger’s Syndrome* can challenge the hierarchical place of this book in autism’s pantheon of key works.

What Kanner came to accept about autism by the 1970s, Asperger had already revealed – only exclusively in German in 1938. War delays impacted still more on his readership, and translation held all up until 1991. Han’s endearing quotable comments about autistics are still being discovered by millions today.

Once you consider the future effects of such buried history, of such a buried people, the scope of the tragedy of a lack of light on the work of Hans Asperger is revealed as crushing. These were courageous men. While Kanner’s heroics are well-known, his escape from unparalleled evil and the 200 he

took to safety with him, we must now also respect Asperger’s astonishing imperviousness to great peer pressures, and not just from the medical establishment. “Twice the Gestapo tried to arrest him, only to be shooed away by his boss, who had taken a liking to him, despite being one of the most prominent Nazis in Vienna”.

NeuroTribes also covers matters from MMR vaccinations to the rise of the Neurodiversity Movement, offering a meticulously researched objective account that not only shatters so many seemingly intractable myths swirling around autism, but with inexpressible compassion and the insights of people on the spectrum and their family members. It captures the passion of autism and autistics, discoverers and parents alike, so authoritatively. This book writes the history of autism for all books to attempt to follow in future. Can you really afford to be without it? I couldn’t. Thank you to Altogether Autism for making it possible for me to read it.

John Greally is a 54-year-old autistic dad, cofounder of Asperger’s Syndrome New Zealand, and currently serves as Kiwi Representative with the peak international body for folk on the spectrum, the Autistic Self-Advocacy Network.



Watch Steve Silberman’s TEDx talk online at https://youtu.be/_MBiP3G2Pzc

NeuroTribes is available for free rental from the Parent to Parent library. Go to www.parent2parent.org.nz/library

Top tips for NCEA Special Assessment Conditions

What are Special Assessment Conditions (SAC)?

SAC provide extra help for approved students studying for NCEA to remove barriers to ensure they are fairly assessed. SAC are used for both internal standards and external exams.

SAC include:

- Additional time to complete work/exams
- Rest breaks
- Reader or writer or both
- Separate accommodation
- Use of technology (e.g. computer).

Why might a student with autism need SAC?

SAC may be needed for a student with autism for the following reasons:

- Handwriting is difficult to read
- Handwriting is very slow
- Behaviour is disruptive to other students
- Require regular breaks
- Obsessive compulsive behaviours may take up assessment time
- Organisational skills and time management skills may mean they do not finish the assessment in the usual time allocated
- Concentration skills may be impaired in assessment situations
- Sameness in routines (e.g. if the student usually has a teacher aide they will probably need one during exams)
- Sensory issues associated with the exam conditions (e.g. large room, bright lights, sound of others' breathing, clock ticking, scratching writing sounds, room with different lighting) may overwhelm the student
- Heightened anxiety, impairing student's ability to demonstrate knowledge
- Anxiety management techniques may disrupt other students (e.g. breathing techniques).

What SAC are students with autism likely to get?

The New Zealand Qualifications Authority (NZQA) categorises autism as a medical condition. Students with autism are likely to qualify for separate accommodation, but the application should specify all categories that apply - learning difficulties, sensory, and physical. If a student with autism has learning difficulties and sensory sensitivities, they need only make one application, specifying all the areas they need SAC.

What does it cost?

It is possible to apply for SAC without any cost to families. While some students have an assessment from a registered professional, SAC applications can be made with school evidence (also known as alternative evidence).

What is school evidence?

School/alternative evidence is information gathered by the school through teacher assessment and observation, at no cost to the student or their family.

How do students apply for SAC?

Schools are responsible for applying for SAC, but parents provide historical information and reports. A key document for families is the Student SAC Historical Record. The ideal time to start completing this form is Year 9.

When do students apply for SAC?

14 March: Applications close for first-time applicants with learning difficulties.

Students with learning difficulties applying for SAC for the first time MUST meet this deadline.

All other students may apply at any time during the year up until the day of the final exam.

2 April: All students with previously approved SAC need their schools to have completed an annual needs analysis and to roll over their existing SAC entitlement or request changes.

1 July – 24 August: Schools talk with students to decide what entitlements are needed for each external assessment and attach the choice to the exam sessions.

1 October: NZQA online applications open for 2017 SAC.

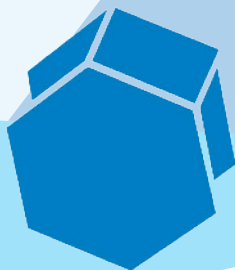
December: Sensory/medical/physical SAC applications for the current year close on the last day of exams.

What happens next?

Once schools have applied online, students can immediately start using the SAC, as the NZQA takes it in good faith that the requested SAC are necessary. If the SAC are later not approved or are changed and the student disagrees with the decision, the school has 15 days to dispute the decision by submitting new information to support their objection.

Altogether Autism thanks NZQA for their assistance. For more information, go to www.nzqa.govt.nz/sac

PRISM



PROFESSIONAL DEVELOPMENT SERIES

DO YOU WORK WITH PEOPLE ON THE AUTISM SPECTRUM?

PROFESSIONAL DEVELOPMENT WORKSHOPS COMING UP!

Prism Professional Development Series is for professionals working with people on the autism spectrum including educators, health professionals and support workers. Developed by Altogether Autism, it is based on theoretical, academic and clinical knowledge, and delivered by specialist facilitators.

All workshops are interactive and present information in ways to appeal to different people, including role-plays, videos, group exercises and discussion. Participants are provided with a comprehensive workbook and ongoing access to tailor-made information.

WORKSHOPS OPEN TO ALL PROFESSIONALS

CHRISTCHURCH

Wednesday 16 March

9am - 4pm

Venue: CCS Disability Action

224 Lichfield St

Christchurch

HAMILTON

Tuesday 12 April

9am - 4pm

Venue: Houchen House

83 Houchens Road

Hamilton

The workshops will offer a safe and supportive environment for people to ask questions about autism. The facilitators will provide best practice skills and strategies to interact in positive ways with people on the spectrum and their families.

\$230 incl GST per person includes morning/afternoon tea and lunch

Funding may be available from Te Pou under the Workforce Development Grants.

Go to www.tepou.co.nz/disability-workforce/apply-for-the-workforce-development-grant/90

TO BOOK YOUR PLACE CONTACT US:

0800 ASD INFO • [INFO@ALTOGETHERAUTISM.ORG.NZ](mailto:info@altogetherautism.org.nz)

OR BOOK ONLINE:

WWW.ALTOGETHERAUTISM.ORG.NZ

