

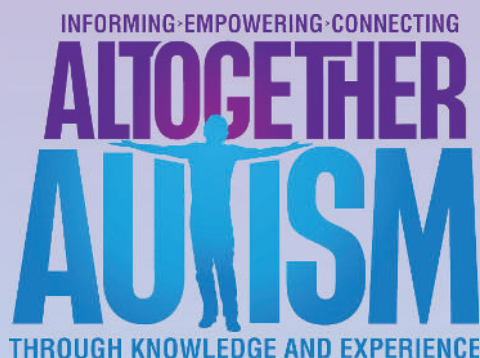
ALTOGETHER AUTISM
JOURNAL
ISSUE 1 2017



Autism-friendly practices
Sugar with your spaghetti?
Maihihi School goes viral

INFORMING. EMPOWERING. CONNECTING.
**ALTOGETHER
AUTISM**
THROUGH KNOWLEDGE AND EXPERIENCE

WE DEBUNK THE VACCINE MYTH



Altogether Autism is a free, nationwide autism information and advisory service provided as a partnership between Life Unlimited and Parent to Parent New Zealand.

With the vast amount of material available online, finding credible information on autism can be a challenge.

Altogether Autism provides tailor-made, relevant, evidence-based information, individually researched and collated by our information and research team. That team has the skills and experience to provide resources from verified sources including our Consumer Reference Group, people on the spectrum and family members of people with autism.

We also refer enquiries to our Professional Experts Group, specialists from a range of professions with clinical experience in autism.

Whether you are on the autism spectrum or you are family/whanau or a professional supporting an autistic person, our service is free.

Contact us at any one of the following links:



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Front cover: Children from Maihihi School, see page 12.

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ISSN 2463-3712 (Print) ISSN 2463-3720 (Online)
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Autism-friendly practices theme



WE SHARE a range of autism-friendly practices in education, health, research and transport on our website and in this the first Altogether Autism journal of 2017.

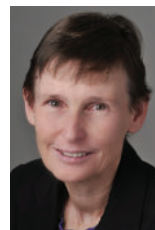
Altogether Autism relies on evidence-based practice when researching and recommending information and strategies.

There are three strands to this evidence; published research, clinical best practice and lived experience. Our Journal reflects these three strands as we include articles from each perspective.

"Nothing About Us Without Us!" is a slogan we are probably all familiar with. The principle behind this catch-cry came out of a worldwide uprising of people with disabilities in the 1980s and aims to ensure that that no policy should be decided without the full and direct participation of members of the group(s) affected by that policy. Ideally this principle should extend beyond policy into practical application. I think it is fair to say that this is easier to preach than to practice. Our aim in focusing on autism-friendly practices in this Journal and on our website is to pay attention to good examples of the inclusion of an autistic perspective across a range of areas, including education, health, research and transport. Taking stock of autism-friendly practices inevitably makes us realise how great the need is for far more specialist tailor-made autism services. We welcome hearing from you if you have examples of autism best-practice to share.

Also in this edition is our statement of position on autism and vaccinations. We base our position on a wide range of published studies that use very robust research methods. Members of Altogether Autism's Professional Expert Group and our Consumer Reference Group considered our position and endorsed it. The first signs of autism may coincide with the time children get the MMR vaccine and for that reason; many families consider there is a link. Some parents report an extreme reaction to immunisation, which may indicate a super-sensitivity to the vaccine. This fits with what we know about sensory sensitivities and autism. However, these experiences do not prove that vaccines cause autism. If we trust scientific method, we must pay attention to the many scientifically sound studies that have investigated this in depth and failed to find a causal link between vaccine and autism. Further details, including website links and references are on our website.

We are delighted to congratulate Anne Wilkinson on her appointment as an Officer of The New Zealand Order of Merit in the 2017 New Year's Honours list. Anne was recognised for her services to people with disabilities and was very instrumental in establishing Altogether Autism in 2007 and continued in a leadership and governance role until her retirement last year.



John Greally, a valued member of Altogether Autism's Consumer Reference Group, retired from this role at the end of last year. John has been a very important influence in the way we do things here at Altogether Autism. He has also worked as an autism advisor on many national projects including contributing to working parties for the Ministry of Health. John and the Consumer Reference Group developed an Asperger's and Gatherings poster available on our website. We wish him well as he continues to advocate for the autism community both here in New Zealand and throughout the world.

Catherine Trezona
National Manager, Altogether Autism

Conference keynote speakers announced

ALTOGETHER AUTISM has announced the first keynote speakers for the 2017 conference which will explore the theme of transitions.

"We are delighted to confirm three speakers, all with an emphasis on strength-based practice," says Altogether Autism national manager Catherine Trezona.



Emeritus Professor Rita Jordan may be known to people who saw her speak on autism and happiness when she visited New Zealand last year.

Prof Jordan has been at the forefront of autism education. Since 1993 she has developed and run a range of programmes in autism studies at the University of Birmingham.

In 2007 she was awarded an OBE for her services to special needs education and in 2014 was given a lifetime achievement award from UK organisation National Autistic Society for her services to autism education.

Also confirmed is Sue Kinnear, a specialist teacher with an endorsement in autism who currently works as a Special Education Needs Coordinator at Hutt Intermediate School.

"Sue Kinnear was a very popular speaker at our 2015 conference, and returns this year with a wealth of educational experience," says Trezona.

Kinnear will be sharing the systems, strategies and practice that she has established to support transitions at the school where she currently works.

"Our 2015 conference was credited with being the autism conference with the highest number of autistic presenters in Oceania, and it is our goal to ensure our 2017 conference is even more inclusive and supportive of autism expertise and leadership," says Trezona.

Jason Edgecombe will share both his lived experience and his expertise as the founder and a mentor at Tauranga-based organisation, Breaking the Label, which provides peer mentoring to people on the autism spectrum.

Each of these keynotes will facilitate a workshop to allow participants to benefit from a smaller, interactive group encounter.

Altogether Autism has also unveiled the logo for the conference, designed by young, Rotorua-based graphic designer Dale Corbett.

Corbett says that some of the words that came to mind when thinking about the logo were growth and progress.

"The cracking of the egg represents breaking out of the comfort zone," says Corbett.

Fittingly, the hashtag for the 2017 Altogether Autism conference is #Breakthrough2017.



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Disability strategy



*The new Disability Strategy helps disabled New Zealanders to participate and contribute to the community. Minister for Disability Issues **Hon Nicky Wagner** discusses its relevance to those with autism.*

IN NOVEMBER last year, we launched the new Disability Strategy.

The vision underpinning the Strategy is a non-disabling society where we all have an equal opportunity to achieve our goals and aspirations.

The direction and priorities outlined in the new Strategy are based on what people with differences, their friends, family and whānau, including many people with autism, said was most important to them during a nationwide consultation in 2016.

The Strategy will guide the work of government agencies on how they can help those with neurodiversity for the next 10 years.

While the Strategy aims to help all people with differences, there are some areas more relevant to those with autism. For example, increasing community understanding of the diverse needs including moving the focus onto a person's abilities rather than what is 'wrong' with them. This includes allowing flexibility in engagement processes, so that autistic people can participate in ways that recognise their different needs.

We know that some people with autism use augmentative and alternative communication (AAC) systems to communicate. One of the priority areas for change is attitudes, which encourages acceptance of a wide range of communication strategies. We want to make sure that the Disability Strategy is put into practice and that real changes are being made. That is why we will be using the Disability Action Plan as the primary vehicle for implementing the Strategy. The Plan will be updated later this year.

A distinctive feature of the new Strategy is that, for the first time, an Outcomes Framework will be developed. This means that targets and indicators will be set to ensure that progress in implementing the Strategy is regularly measured. People with autism will have an opportunity to provide feedback on the draft Outcomes Framework during public consultation later in the year.

Autism-friendly healthcare: Empowering autistic adults and support persons to inform and transform autistic healthcare



Ava Ruth Baker (MB ChB Dip Health Sci – Mental Health) has experienced autistic healthcare ‘from both sides of the desk’ – as an autistic adult, parent, and a medical practitioner now specialising in autism and mental health, after decades as a GP. Among her other autism work, she offers training workshops on ‘autism-friendly healthcare’ for medical practices. She is on the board of the ASK Trust and can be contacted via arbak@clear.net.nz

DO YOU DREAD or avoid visits to your GP, hospital, dentist or other health provider? Research is finally confirming what many of us have long known, that there are major barriers to good healthcare for autistic patients compared to the general population (Nicolaidis et al, 2013).

The New Zealand Autism Spectrum Guideline acknowledges this disparity, and recommends all health providers upskill and adapt their practice to autistic needs – but stops short of practical ‘how to’ resources to enable this. Health providers so far show limited interest in taking up opportunities to upskill, and though licensing bodies such as the NZ Medical Council now expect practitioners to demonstrate ‘cultural competence’ and to accommodate ‘health literacy’ issues, offering incentives to attend courses in the needs of ethnic communities, this has not been extended to the needs of the neurodiverse community.

The focus of this article is on ideas and resources that you – autistic adults, parents and support persons – could use in the meantime to ease your own healthcare encounters, and in the process to help educate health providers about autistic needs.

EXCITING INSIGHTS AND SOLUTIONS are emerging from the work of AASPIRE, the USA-based ‘Academic Autism Spectrum Partnership in Research and Education.’ Through their ‘co-research’ approach (see article on autism-friendly research on page 5), AASPIRE have completed a series of studies exposing and exploring this disparity, then developing and evaluating a ‘healthcare toolkit’ to address that. The toolkit itself, as well as academic articles detailing their research, is freely available from their website.

“Autistic adults face many challenges when trying to access healthcare services, including locating disability-competent providers, understanding and navigating the health system, and obtaining the necessary accommodations for their communication, cognitive, emotional regulation, and sensory needs. We developed tools to help autistic people and their healthcare providers address these challenges.” (Nicolaidis et al, 2016).

THE AASPIRE HEALTHCARE TOOLKIT has one section for patients and supporters, and another for healthcare providers, providing a comprehensive range of downloadable healthcare and autism-related information, checklists, worksheets, and other resources.

For autistic patients and their support persons, these include

- ‘AHAT’ (Autism Healthcare Accommodations Tool) – an interactive computerised survey that generates your own customised accommodations report to give your health provider
- ‘Symptoms’ worksheet outlining the types of questions healthcare providers are likely to ask you about your symptoms, to help you prepare for your visit beforehand; and other worksheets for ‘What to bring to a visit’; ‘Making

- an appointment’ and ‘After the visit’
• information on your rights in healthcare

This toolkit has been already found to help autistic users “clarify and communicate their needs ... self-advocate and prepare for visits more effectively, and positively influence provider behaviour.” It also helped users “name the challenges they experience with healthcare, and understand them as issues commonly experienced by others on the spectrum ... [reframing them] not as personal weaknesses, but as disability-related needs that can and should be accommodated.” (Nicolaidis et al, 2016). Although their toolkit was developed for use in general practice / primary care, it’s been found useful in other healthcare setting too.

“This type of patient empowerment appeared to be particularly helpful when combined with practical resources and tools that participants could use to prepare for visits or for following recommendations But patient empowerment must be coupled with changes in provider attitudes, skills, and behaviours” (Nicolaidis et al, 2016).

OTHER SUPPORTS FOR HEALTHCARE ENCOUNTERS

Meanwhile in New Zealand, Autism Spectrum Kiwis (ASK) Trust has made our own compilation of international and local healthcare resources, to support your healthcare encounters, with tips and links, including some suitable for autistic children, for autistic adults with limited understanding of basic health matters, and for use in other healthcare settings such as hospitals, dental offices, or when preparing for specific procedures such as blood tests.



References:

Nicolaidis et al (2013). Comparison of healthcare experiences in autistic and non-autistics adults: a cross-sectional online survey facilitated by an academic-community partnership. *Journal of General Internal Medicine*, 28(6), 761–769

Nicolaidis et al (2016). The Development and Evaluation of an Online Healthcare Toolkit for Autistic Adults and their Primary Care Providers. *J Gen Intern Med* © Society of General Internal Medicine 2016; DOI: 10.1007/s11606-016-3763-6

Autism-friendly research: An equal partnership between academics and autistic adults?

Ava Ruth Baker (MB ChB Dip Health Sci – Mental Health) is the only NZ-based member of the Autism CRC Research Academy, she is actively engaged in, and available for, autism research co-production projects. Shouldn't the slogan "Nothing about us without us" apply to autism research too? asks Dr Ava Ruth Baker.

THE EXCITING news is that the phrase 'Nothing about us without us' is finally catching on when it comes to autism research, albeit slowly.

So far in only a few centres overseas, a leading one being Autism CRC (The Cooperative Research Centre for Living with Autism), who handle the majority of Australian applications for autism research funds.

'Co-production' is now one of their main criteria for approval.

In 'research co-production', also known as 'peer research', researchers and autistic adults work together as peers, to ensure that what is being researched, and how, is "relevant to, and appropriate for, those on the spectrum and their communities. Expertise gained through lived experience, and research skills, are equally respected and valued. (Autism CRC, 2016a)

Though the potential benefits of research co-production is now acknowledged in the academic literature (e.g. McDonald & Raymaker 2013; Pellicano et al 2014), there's also evidence of "resistance by researchers to engage in co-production with people on the spectrum" (Autism CRC, 2016a).

There are a number of programmes and downloadable resources available to facilitate autism-friendly research. They include:

TRAINING IN CO-PRODUCTION FOR RESEARCHERS AND AUTISTIC ADULTS:

In 2015 Autism CRC established a Research Academy offering training to "upskill both autistic adults and existing scholars to be able to work together as peer researchers" (Autism CRC, 2016a). I was delighted to be accepted into their inaugural training and would thoroughly recommend it!

INCLUSIVE RESEARCH PRACTICE GUIDES AND CHECKLISTS

This world-first set of guides and checklists was co-produced by Autism CRC "to help researchers be more inclusive at all stages of commissioning, undertaking research and disseminating, evaluating and utilizing findings" (Autism CRC, 2016a)

VISUAL DICTIONARY OF RESEARCH TERMS

(Autism CRC, 2016c): a co-produced visual dictionary to explain common research terms for those who prefer visual language.

References:

Autism CRC (2016a) Autism CRC Research Academy Report <http://www.autismcrc.com.au/reports/autism-crc-research-academy-report>

Autism CRC (2016b) Inclusive research guides and checklists <http://www.autismcrc.com.au/inclusive-autism-research>

Autism CRC (2016c) Visual Dictionary of Research Terms <http://www.autismcrc.com.au/download/1175/Visual%20Dictionary%20of%20Research%20Terms%20Final.pdf?redirect=node/559>

McDonald, K.E., & Raymaker, D.M. (2013). Paradigm shifts in disability and health: toward more ethical public health research. *American Journal of Public Health*, 103 (12), 2165-2173.

Pellicano, E., Dinsmore, A., & Charman, T. (2014). Views on researcher-community engagement in autism research in the United Kingdom: a mixed-methods study. *PLoS One*, 9(10), e109946. doi: 10.1371/journal.pone.0109946.



OPEN LETTER TO RESEARCHERS: AUTISTIC DISSATISFACTION WITH CURRENT PRACTICE

We autistic members of the Autism CRC Research Academy feel strongly, as a group, that our prior experience with research projects and researchers has been more negative than positive. As a result we wrote an open letter to researchers detailing what we had experienced, and what we need from them:

To increase positive experiences of research participation we need:

- Communication on both sides – a willingness to really understand what we are saying and a willingness to adapt communication strategies to meet our needs;
- Explanations that we can understand in a format that makes sense to us;
- To be treated individually and flexibly, not based on a stereotypic view of autism; and,
- To know how to give researchers feedback and be honest about our experiences

To help ensure our effective participation we need researchers to:

- Ask us questions instead of assuming what we might mean (e.g. asking us "what do you mean by that?");
- Understand that we may need support, such as from an advocate / buddy / mentor to help us get our message across during interviews or research sessions;
- Enable us to have something written to help us respond to questions so we can read or use this if necessary, this can be facilitated by providing questions ahead of time, so that we can consider our responses rather than being put on the spot.

Concluding **"We are keen to engage as peers with autism researchers, to be involved in research teams, advisory groups and provide feedback on research tools and approaches."** (Autism CRC 2016a, Appendix D)

Altogether Autism 2017 Conference

19 - 20 July, Holiday Inn Auckland Airport

Supporting and empowering autistic people to make successful transitions

Keynote speakers



Emeritus Professor Rita Jordan from the University of Birmingham has been at the forefront of autism studies. She was awarded an OBE in 2007 and given a lifetime achievement award from the National Autistic Society in 2014.



Sue Kinnear works as a Special Education Needs Coordinator at Hutt Intermediate School. She will be sharing the systems, strategies and practice that she has established to support transitions at school.



Jason Edgecombe will share his lived experience and expertise as the founder and a mentor at Breaking the Label, a Tauranga organisation that provides peer mentoring to people on the autism spectrum.

Registrations

Early bird

until 31st May 2017

Personal individual \$320

Professional \$540

Regular

from 1st June 2017

Personal individual \$420

Professional \$640

Register online at

www.altogetherautism.org.nz/conference



Transitions
#Breakthrough2017

ALTOGETHER
AUTISM

Bridging the gap

'Supporting and empowering people on the spectrum to make successful transitions as they navigate new challenges on the journey through life.'



Speech New Zealand teacher, examiner and trustee **Claire Marsh** of Morrinsville shares an experience she had recently with a confident autistic boy sitting a speech exam.

SPEECH NEW ZEALAND is an examining organisation that aims to empower students to develop versatility in the use of language and oral presentation and performance skills.

It provides a range of examination topics including:

- Speech and drama
- Public speaking
- Theatre-in-Action
- Oral communication in schools

Either a speech and drama teacher within the school teaches students sitting these exams or they have private tuition.

As an examiner, I recently had a delightful and inspiring experience when examining a group of three boys sitting the grade 4 exam.

The requirement for the first exercise was: 'Give an informative talk on a topic of interest you have researched.'

One of the boys, John*, selected to talk about autism. He had prepared a creative chart that reinforced his main points, had depth of knowledge and engaged his audience throughout the talk. He concluded with the words:

'I know about this, because I have autism!'

He was confident, fluent and both informed and inspired his audience. While John had confidence in mastering skills of communication, not all students on the spectrum are as assured. Speech New Zealand encourages students with learning differences to sit grade examinations either under the general syllabus or under the Certificate of Attainment.

The Certificate of Attainment may relate to a candidate with any learning difference, which may affect their performance if the examiner is satisfied that they are doing the best work of which they are capable.

One of our teachers shared the processes she uses when teaching students on the autism spectrum. She finds rapport can be more easily established with these students by working one-on-one with them. Once she has established some trust they start to play with objects, materials, properties and start developing imaginative exchanges. She leaves the initiative entirely with the student.

After a few sessions of connecting in this way, the trust and confidence usually develops quickly and the teacher can start shaping techniques for activities working with a friend or a small group of neurotypical students. This teacher is amazed at how quickly the autistic student gains confidence and extends their creativity by being part of a group.

*not his real name

Speech New Zealand
For more information contact:

Speech New Zealand, P O Box 12023, Wellington 6144

Telephone: 04 498 9660

Email: info@speechnz.co.nz

Website: www.speechnz.co.nz

Mind over manner: empowering our parents to stay buoyant



*As children on the Spectrum reach adolescence, it is important to recognise the increasing needs of the parents, family, teachers and other professionals who are in close contact with these individuals. **Susan Haldane**, the driving force behind MIND OVER MANNER, is a parent of a teen on the Spectrum and discusses the workshops she runs.*

WITHIN THE first five minutes of a MIND OVER MANNER workshop, we have our 150 participants breathing a collective sigh of relief as we all unanimously agree we are not attending this event so we can 'fix' our child.

Phew! The very thought of it is exhausting.

This is an impossible task and we all know it! We all live it!

We are all here in the same room, at this MIND OVER MANNER workshop recognising our difficult family experiences or school experiences are not so isolated or obscure after all! We are all here to find out ways to stay buoyant.

So what does MIND OVER MANNER do?

It delivers specialist workshops designed to engage and develop communication capabilities of those who learn, think and work differently and it facilitates workshops for parents, families and professionals in the workplace along with community to advance communication and behavioural functionality.

The workshops are successful because we use a different approach by working with theatre practitioners.

We reconstruct and deliver "active-reality" scenarios from life experiences so parents, family, caregivers, teachers, youth workers and police have the chance to participate and reassess their responses to these most difficult times.

Sensory processing and cognitive differences in children are presenting at an accelerated rate.

The behaviours are often confused leaving us no choice but to address their discomfort and find ways as parents to shift and adjust.

No standard parenting books work, the children are emotionally and physically uncomfortable and as parents, we know they will not "get over it". They will not back down because what they are feeling is real and it can be terrifying or overwhelming.



As my child reached adolescence, I came to recognise the increasing needs of the parents, family, teachers and other professionals who were in close contact with him. The strength and stability of all these people in their interactive role was a fundamental contributor to the positive development of my teenager. And to the maintenance of myself as a buoyant parent.

GENEROSITY

Our first change as parents is to be generous in ourselves sometimes beyond what seems fair. However, we are the first movers.

Get objective, rise above the moment and recognise that we are the demonstrators of flexibility.

That is our job.

It is we as parents who need to make the shift. Not completely but we have to make the first move.

Once our children see we can make a shift then they recognise they can be safe enough to shift as well.

Not only are we unravelling their constant fear and inflexibility but also their inability to respond to authority. Our social structures are often based on rules some obvious and some more hidden. As we know authoritative measures do not work with our children but suggestion and generosity will.

BELONGING

In 2014, I spent time in the Black Hills, South Dakota with Temple Grandin, the psychologists and educational experts from Reclaiming Youth International and the Native American Sioux Medicine People.

While this course catered to teenagers who had been in foster homes throughout their childhood, I was interested in the application of "Belonging" and how it applied to our new sensitive youth estranged from it because of their neurological differences.

The belonging comes externally for them, primarily through application rather than direct connection with another; through the personal soother, the familiar, the music, the spinning, through the instigation of their appropriate and individual time frames, through their opportunity to self-learn, through their special environment that takes out all "over stimulus". Once they create their internal belonging then the connection through the one or two people they trust can become the next stage of finding belonging.

STAY OBJECTIVE

We must objectify what we are doing in a process. We are enabling the sense of belonging and providing generosity and showing the capacity to shift.

This objectivity prevents us as parents from becoming emotionally engaged in the difficulty, from being frustrated at the time it takes to "go the long way round" and from being outraged at the way we are sometimes treated. Objectivity maintains buoyancy.

CREATE A SELF CARE CHECKLIST

At different times in your parenting cycle your self-care needs will differ. Learn to recognise these...when you need to be alone and when you are just "hiding from the world".

Continued page 8



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When you feel strong and brave and when you are not managing, if you accept all of these as parts of a cycle, then you know you will come back up again. You learn to understand yourself as part of the growing process and this keeps you buoyant.

We all know that post a "meltdown" a family or relationship argument will often follow soon after. If we view this as the "transfer of energy", we can create protective measures to avoid the meltdown affecting other relationships in the family.

It is essential, post meltdown, that no one speaks. No one comments. Everyone must take their space and individuals must create their own self-care strategy. Let the energy pass out, open windows, shower, and walk, play music, write it down but do not engage with each other for a set time. If you have another sibling set them up with an activity ensuring you still take out the words. This is so you all re find your essential sense of self. If there is physical damage let the clean up happen together once the family and individuals are soothed.

If possible, be silent for at least 30 minutes.

When there is a meltdown brewing take out all words. The person is overwhelmed and is often unable to hear anything. Hold up a flashcard to suggest the "soother" or to connect "I am here for you".

The flashcard is also good for parents to use for recovery after meltdown.

"I am going to walk for 30 minutes. When I return we can clean up together. I love you"

Sometimes it is too frustrating to try to communicate using verbal language. Texting an idea or list can provide a way to get a message across where the teenager can have the space to absorb and decide from afar to comply with your idea or suggestion.

ISOLATION

As parents, we can parallel the exclusion our children are experiencing and can become more and more reclusive ourselves. As our children become teenagers, we do not go to the parents' impromptu barbeque while the teens go to the movies, because our teen was not included. People can hurt us, as they do not understand.

More and more I found there are people who did understand, but they were outside of these school social realms. My son's special interests and the mentors I found for him (often older and wiser people with more time to recognise and place value on what he could offer) were my links to people.

I also created my own personal friendships outside of the school social sphere that were separate and meaningful to my special interests and me.

HOW TO ASK FOR THE SUPPORT YOU NEED

My closest friends were not the ones who said: "you need a break. You need to get away". The supportive friends knew that the best relief they could bring me was to form a true connection with my son. This alleviated the exhaustion of being the sole communicator with my son, it alleviated his loneliness and it alleviated the loneliness that I felt because of his loneliness.

This was the break I needed. There are great people out there who know kindness and who will walk, talk, and interact on a one to one basis with your child. People come and go in our lives so it is important to accept these people come for pockets of time.





PEOPLE SUPPORT

Over the years, so many people have said to me “I don’t know how you do it! You are amazing! I could never do what you do!” Now we all know these people are intending to support and care for us but in all truth, what we are receiving is “Gee your life is so bad. It looks awful. I wouldn’t want to be you”

I have the most ghastly feeling when friends say this. Within the MIND OVER MANNER workshops, we find ways to rise up out of this. As parents, we must keep ourselves buoyant and still acknowledge that this person is genuinely intending to be caring.

In these moments I quietly thank the person for their care, I point out that many people have made similar comments and that the statement they are making is a strange one because while they intend to be caring it is making me feel like I have a “bad lot”.

I acknowledge, “Yes there are difficulties and I then say the reason I have got through and the way I maintain my strength is because people like themselves are standing beside me and giving me support.

I acknowledge that their support and care for my child and myself is invaluable. By delivering this response with quiet affirm, they receive it as an acknowledgement and as a compliment. At the same time you have not allowed this statement to deflate you and you will have retrieved your buoyancy.

RADARS

Our children are like radars. Their senses are operating differently. I have come to observe and understand they notice how a situation or person feels...almost electrically. If we start to think of the space in between two people...the electrical field, and if we were to picture it in our minds, we can then use our mind to soften it....actively.

This is a bit like horse gentling. It takes out all words and eye contact, personal emotion and it is a process to activate another sense...our radar sense...for the space in between our child and us. Once we become aware of the energy, we generate outside of our bodies it can somehow moderate the energy and emotion going on inside our bodies. This technique helps me calm down when I am not even necessarily aware of how upset I actually am.

ADVICE FROM OTHERS

When people do not understand sensory and cognitive diversity, they often try to help us by telling us: “You should” or “tell him he has to” or “He’s got to”.

We all know that our children do not respond to “should” or “telling” or “got to”. This area of “friend incompetence” can become a huge place to dump your anger. Be aware of how you respond, stay gracious and teach them about declarative rather than imperative language!

The main thing is the intent of the communication. In declarative communication, the intent is to share our experiences.

A response is invited but not demanded. Declarative communication is open-ended; there is no right or wrong way to respond. In imperative communication, a particular response is expected.

Imperative:

Pick up your shoes

Declarative:

I think you will have cold feet if you go outside now

Imperative:

Don’t forget your phone

Declarative:

Hmm, I wonder what you are planning to do in the car

SCHOOL SUPPORT

As you strengthen in how you stand in your parenting, you will learn to ask for what you need in the school environment. It is up to you to frame your child’s learning environment to be strength based. As the school days become overwhelming and the programme needs to be changed make sure the school does not call it a “reduced programme”.

Your child will most certainly “feel” this. Set it up as a Specified Enrichment Programme and make sure your child has the opportunity to grow in his special interest area.

This is an opportunity where a voluntary mentor could facilitate your child in finding positive threads of specific learning. Often you can use the specified learning as the connector to create other learning experiences.

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The mentor must not be you as a parent. This is so you maintain your resources for parenting but also so you do not take away your child's opportunity to have another human relationship through his special interest.

TIME STRUCTURES

Observe how your child fits in with the set time structures you have in your lives. Where they do not work so well see what you can do to create more flexibility. This is difficult, as we all have to meet timelines and deadlines. But consider for example if it's possible to leave the house one hour later on a Wednesday so in the middle of the week your child can have a morning breather and gather himself so he can manage himself to the end of his week.

NEGATIVE WORLD VIEW

With the stresses that come around neuro diversity it can be easy to fall into a negative world view, each individual can fall into these traps. Just watch out for them. Be cautious not to blame others and avoid thinking the worst-case scenario. Adjust to a more positive framework where you can.

Behavioural problems in teens can lead to behavioural reactions in adults

Make sure you respond and do not react.

CONCLUSION

I have endeavoured to share some of my observations as a parent. I can say through the care of others, through established mentors and through dedicated work from myself, my family and good friends my son has the capacity to have independence, drive a car and to run his own business in his special interest "bamboo as a global resource."

The work with these children is evolving. If you have a child with neuro diversity this becomes your work. It is family work. It is community work. It contains new science, the potential for new ways of relating not necessarily based on language, new social structures, and new shapes in time. We must become curious and open and we must take up a bigger perspective.

It is part of who we are in the moment but it is also about what we are creating for our new youth and for our future.

Susan Haldane, the driving force behind MIND OVER MANNER, has worked as a freelance actor, director, singer and teacher for 30 years. Her work has focussed predominantly on youth and their development of social confidence and flexibility. Susan has facilitated theatre workshops with refugees, multicultural and differently abled groups – and used communication role play techniques extensively in schools, prisons, with legal, medical and other professional groups and with kids on the street.



Altogether Autism says no links between vaccinations and autism

There are concerns the release of controversial anti-vaccine movie Vaxxed in New Zealand will result in more children missing vaccinations. Recently many people questioned the link between autism and vaccinations again. Altogether Autism's stance is there is no link.

A CAUSAL RELATIONSHIP between autism and vaccinations has been widely discussed since the 1990s, with Measles-Mumps-Rubella (MMR) and mercury (in the form of thimerosal) the primary areas of concern.

Much of the controversy around MMR vaccine and autism followed the work of Andrew Wakefield and colleagues (1998), published in the respected medical journal, The Lancet but later retracted by the Journal in 2004 for both scientific and ethical flaws.

Wakefield was struck off the UK medical register for his fraudulent paper and widely discredited.

Many well-researched, peer-reviewed articles in well-established journals have disputed the idea that MMR causes autism. Following the 1998 publication, a lot of research was conducted in this area, which was unable to replicate the results. For example:

- **1999:** A study of 500 children found no link between autism and vaccines (Taylor et al., 1999)
- **2002:** A study from Denmark of 537,000 children found no link (Madson et al., 2002)
- **2002:** A study from Finland of 535,000 children (Makela et al., 2002) also found no link.
- **2004:** The Lancet, the publisher of the original Wakefield paper in 1998, released a statement refuting the original findings, saying "They had conducted invasive investigations on the children without obtaining the necessary ethical clearances... picked and chose data that suited their case; they falsified facts" (Horton, 2004).
- **2005:** A review of 31 studies covering more than 10,000,000 children, also found no link (Demicheli et al., 2005)
- **2012:** A review of 58 studies including five randomized controlled trials covering over 14,700,000 children also found no link (Demicheli et al., 2012).

Maglione et al., (2014) identified that despite numerous studies confirming the lack of association between MMR and autism, parents continue to be concerned about vaccinations. The purpose of their research was to review a wide range of studies to summarise the evidence and to rate the strength of the collective evidence. They found that some vaccines are associated with serious adverse events, for example, they found a high association between MMR and anaphylaxis in children with allergies, and febrile seizures (i.e. convulsions triggered by high temperatures). They did not find evidence of the MMR vaccine being associated with autism, and in fact found high evidence that MMR is NOT associated with the onset of autism in children (Maglione et al., 2014).

There is no scientific evidence to support the claims of a causal relationship between MMR and autism.

A lot of the concern surrounding vaccinations leads back to mercury and thimerosal particularly. Thimerosal is a mercury-based preservative used in some vaccines and other pharmaceutical products. Thimerosal has never been present in the MMR vaccine used in New Zealand and has been phased out of all vaccines used in New Zealand since 2000, including the current influenza vaccines (Ministry of Health, 2016). It is however, still used in some vaccines overseas. The global increase in ASD diagnosis has not been linked to mercury

The much-publicised "evidence" by Andrew Wakefield linking autism with vaccines was found to be fraudulent, the author was disgraced and fired.

exposure apart from in isolated cases so it cannot possibly be causal to the increased prevalence of autism diagnoses worldwide.

Mercury has been identified as toxic for centuries, with most of the environmental mercury coming from coal-fired stations, waste incinerators and mining (Gorini, Muratori & Morales, 2014). Methyl mercury (MeHg) is the most widespread source of mercury exposure, and occurs most commonly through the diet, through fish consumption (Wisnjevce et al., 2013, as cited in Gorini et al., 2014; Kern, Geier, Skyes, Haley & Geier, 2016). There is some evidence to suggest that maternal consumption of fish may impact children's language, IQ, memory, attention and visual-spatial and motor skills (Grandjean et al., 1997; Crump et al., 1998; National Research Council 2000b, as cited in Gorini et al., 2014). There are some studies that suggest methyl-mercury may potentially be involved in autism development but there is by no means consensus and further research is needed (Gorini et al., 2014; Kern et al., 2016).

Despite there being recognised neurotoxicity of mercury there is no established link whatsoever between thiomersal in vaccines and any adverse effects, and no causal relationship has been found between thiomersal and autism.

As stated by David Newman, chair of the Paediatric Society of New Zealand (personal communication, March 7 2017), the key fact is that even if thiomersal was linked to autism (which it is not) New Zealand childhood vaccines have not contained thiomersal since 2000 making it impossible that mercury in vaccines is in any way linked to the reported increase in autism diagnoses in New Zealand.

Summary

The one study (Wakefield, et al., 1998) that suggested vaccines caused autism has been discredited many times by scientific research and the original article has been officially retracted. The research evidence therefore strongly supports a lack of association between autism and vaccinations.

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Principal's note sends tiny school viral



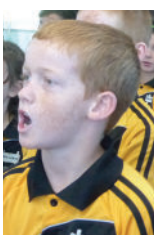
*When Maihihi School principal Glenn MacPherson slipped a note and a parcel into Cam Uden's school bag in October last year, little did he know that simple gesture would put the small King Country school on the global map. **Mary Anne Gill** visited the school recently to find out what is so special about Maihihi.*

MAIHIIHI SCHOOL principal Glenn MacPherson noticed 10-year-old Cam Uden had started demonstrating good hand-eye coordination when it came to cricket.

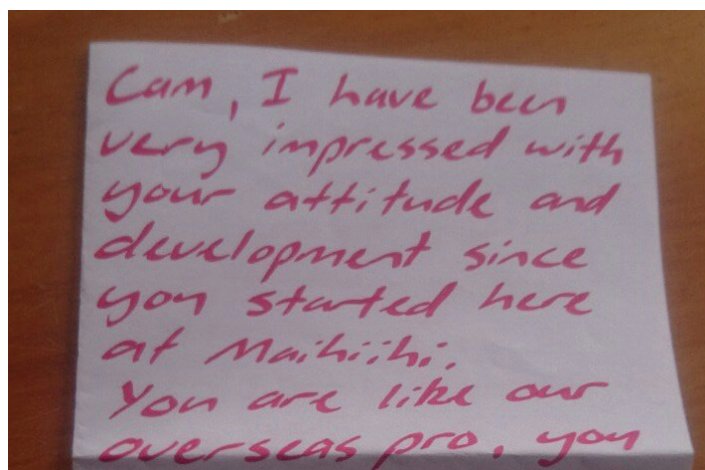
He knew Cam's family loved the game and says he thought "every now and again you see a kid with a little bit of need".

So he wrote Cam a note and gave him a sports t-shirt which Northern Districts overseas import cricketer Ben Laughlin had worn.

"Cam I have been very impressed with your attitude and development since you started here at Maihihi. You are like our overseas pro, you offer our school so much in many different ways. This little gift is future focussed. It will not fit you now but when it does, I would like you to look me up and come and tell me what career path you have chosen. I am guessing it will be something to do with technology, maybe computer programming or game design!! Maybe even a job that doesn't exist yet. Mr Mac"



Cam Uden



Cam's father Jason could not believe it. An avid Twitter fan – his best posts before that had featured the jokes he wrote on his son and daughter's sandwich bags – he tweeted to his followers:

"Maihihi primary have adopted our quirky son who has autism with such love and acceptance. This came home today."

It went viral on social media including metro.co.uk.

To his followers Uden said: "Yeah in a time when education cops a hammering it's great to be reminded of how special most of them are."

The fuss seems to have passed Cam by. Four months on, he is a house leader with a degree of confidence his parents find refreshing.

The first thing you notice when you pull up at Maihihi School, about 20 kilometres east of Otorohanga tucked into rolling King Country farmland with a mix of dairy, sheep and beef, is the impressive sign with its motto "Nothing great is easily won" and the high green fence that prevents "bolter" children from getting out.

"We are fully fenced here. If a kid has a melt down here, they're not going anywhere because they are safe in our grounds," says MacPherson.

Maihihi has another child on the spectrum at the school – 7-year-old Erin Kelly.

One is entitled to funding from the Ministry of Education, the other isn't.

MacPherson has a novel approach to educating children on the spectrum developed as a child when his mother Cathryn taught children with learning differences at Tokoroa Intermediate and the Down syndrome pupils joined the family on their holidays at Rotorua's Blue Lake.

"We taught them water skiing, swimming, everything really. It made me realise that it's all about treating kids equally and making school a fun place to be."

MacPherson was born in Dannevirke and grew up in Tokoroa with his mother and father Murray (then a farmer, now a truck driver) and two brothers, one of whom also became a school teacher.



He started teaching in 1999 working in Wellington, Liverpool UK, Upper Hutt and in Hamilton. When the Maihihi board of trustees interviewed him for the Maihihi job three years ago, he knew that is where he wanted to be.

During the 35-minute commute from his home in Cambridge, where he lives with Vanessa and three children (Macy, Hadlee and Jossy), to Maihihi, he challenges himself to make a difference in the school children's lives.

"School has to be that safe zone for them. All children need to feel welcome and included here."

Good teachers are the key too, he says.

"A general teacher has to be everything: doctor, psychiatrist, counsellor, you name it.

"You can spot the good teachers.

"They get to know their kids and the kids know they really care. It's about setting high expectations for them and it's the same rules for everyone.

"No one here is put on a pedestal and if they break the rules, they get the opportunity to right the wrongs."

The Government is set to release new guidelines on how to deal with challenging behaviour. Some schools use seclusion rooms, which the Ministry of Education and Altogether Autism do not favour.

MacPherson concedes some children need careful managing.

"You can't let them hurt themselves or others; there are better ways of handling them though than putting them in a seclusion room. You've got to treat an autistic child the same as every other child in the school.

"Locking them away is not the answer. Building relationships with the children and their families is vital."

When Cam has issues at school, teachers give him noise-cancelling headphones to wear.

He also has his own space within the classroom with his own beanbag.

That means Cam is out of a situation but is still within the classroom environment.

"All our Maihihi students are great kids; they are unique and different in so many ways, yet function so well as a whole unit."



TUCKING IN: Maihihi School principal Glenn MacPherson joins students for lunch.

Sensory and anxiety concerns within an inclusive educational environment



Altogether Autism published its stance on the use of seclusion in schools (Issue 4, 2016, p.12). In the following article, Sue Kinnear, Wellington-based Special Education Needs Coordinator and a specialist teacher of autism, describes her implementation of a sensory room as respite from overwhelming situations for her students as an alternative to seclusion.

EDUCATORS AIM for inclusion of all students in educational environments and meet their individual needs. How do we provide support for students with sensory and anxiety challenges when the classroom environment itself is the catalyst that affects their ability to process the stimuli that they are receiving?

Our role is to support students in the learning but how do we manage their personal challenges?

I was motivated to change in 2009 with the knowledge the following year three of my students would transition onto an Ongoing Resource Scheme.

The creation of a special environment at our Wellington intermediate school called a Sensory Room required us to work out the practice and facilitation of using it.

Background information collected from transition meetings and Sensory Profile Assessments identified that each of the three students had complex individual diagnoses including autism, and sensory sensitivities and anxiety.

The assessments made recommendations of how we could address and incorporate the sensory needs in a classroom environment within each of the student's daily programmes.

The question was how to respond and provide support before, during and after the students' emotions, anxieties and behaviours had reached extreme levels of personal distress.

In consultation with family and specialists, we decided that a room that might support sensory needs had the potential to support the students.

It became clear that I needed to develop procedures around the use of the room.

I made a conscious decision to use the title, "Sensory Room." The role of multi-sensory rooms is to increase sensory awareness, often with lots of lighting effects. The title "Sensory Room" avoided the inference that multiple stimuli were the only option.

I had a clear vision. We had potential to support students with heightened levels of anxiety or sensory sensitivities.

I had four priorities:

1. Establishing a relationship with the student
2. Meeting the needs of the student
3. Establishing clear expectations
4. Encouraging the return to class and engagement in learning.

The aim was to contribute to the student's understanding of their individual needs so that they could learn how to react and respond to their personal challenges with resilience and increase their abilities to "manage self", New Zealand Curriculum key competencies (MOE, p.12).

CREATION

Multi-sensory rooms often use white walls to project lighting onto them. I decided to choose an alternative colour pallet of cream and navy. Rather than using a light colour on the walls, I decided that the floor, walls and curtains would be navy. I wanted students, if they wanted to, to have the ability to minimise light.

Playing DVDs with calming visual scenes such as nature, aquariums, beach walks or space adds lighting.

DVDs can also provide audio choices in volume and/or style of music or sound.

Soundproofing in the walls, ceiling and door allows an element of control over the level of sound from outside the room.

If people prefer to sit or lay on the floor the extra underlay and soft carpet allows you to do so comfortably. We modified the original building specifications to install a stronger support beam and higher quality metal fixtures to hold a swinging feature that can accommodate up to 200 kilograms.

The sensory room has two doors and students are able to exit either door at any given time. It is not a punitive room.

SKILLS OF THE FACILITATOR

I identified the characteristics that I was displaying in the role as a facilitator and found it was necessary to work on the following:

- Develop a genuine relationship with the student
- Use short clear phrases
- Adapt the tone of your voice to each scenario
- Adapt your physical energy to each scenario
- Be aware of how you move
- Introduce visuals to increase communication if necessary
- Use redirection
- Encourage student advocacy.

All of these actions had an impact. You might think that success could be specific to one facilitator, but through a modelling and coaching process, I now have teacher assistants and teachers who also follow the same approach with equal success.

Facilitators encourage students to communicate their choices and action them whenever possible. If the student's preference is to use a calming DVD, they are encouraged to turn the equipment on and begin the choice process.

Redirection of attention can have a positive impact on a student's emotions and physical energy. It may also contribute to a feeling of control and autonomy.

We reviewed expectations of positive behaviours. Students are encouraged to set time frames and these range from 10-minute breaks up to 20-minute breaks. The students understand that they will return to their classroom or a quiet space of choice to re-engage in learning.

The facilitator leaves the sensory room and sits within sight of the small viewing window. The safety of the student is paramount and facilitators are responsible for supervision. At the end of the session, the facilitator gently knocks on the door to alert the student that someone is entering the room and that transition back to the classroom is about to begin. If the lights are off, we take care to introduce the light gently by using the dimmer switch.

Multi-sensory environments and their use by people with autism

A multi-sensory environment is an artificially created room or space designed to allow those using it to control sensory input, including sound, lighting, smell, touch, temperature and space. Multi-sensory equipment is used to stimulate the senses and promote pleasing sensation and feelings of well-being.

THE ORIGIN and history of multi-sensory rooms can be traced back to the Netherlands in the late 1970s where psychologists Ad Verheul and Jan Hulsegge developed them as a therapy for individuals with severe disabilities.

Originally named as 'Snoezelen' by the founders, it is now being widely referred to as 'multi-sensory rooms' or 'multi-sensory environments' (MSE). The term "snoezelen" (pronounced like "SNOOzelen") is a neologism formed from the Dutch "snuffelen" (to sniff, to snuffle) and "doezelen" (to doze, to snooze).

Over the years, the concept has become popular in the UK and Europe where multi-sensory environments provide a wide range of sensory stimulation for people with a variety of disabilities, disorders and conditions, and are a part of special education curriculums.

Those who can benefit from multi-sensory environments include children and adults with learning differences such as autism, cerebral palsy, intellectual and multiple disabilities, people with brain injuries, dementia sufferers, and people with mental health issues including stress or anxiety problems.

A multi-sensory environment is an artificially created area, such as a room or a pool or a garden, which contains equipment and materials designed to stimulate the senses through light, sound, touch and smell.

It aims to create a feeling of safety, and to provide novel sensations, with stimulation being under the user's control. Items used in multi-sensory environments include things like ball pools, bubble tubes, optic fibre taillights and musical effects in one place. Multi-sensory rooms do not rely on verbal communication and may be beneficial for people with profound autism, as it may provide stimulation for those who would otherwise be almost impossible to reach.

Providing a stimulating environment can:

- Increase concentration and focus attention
- Develop or reactivate senses of hearing, sight, smell, touch, and taste
- Heighten awareness and improve alertness
- Improve coordination and motor development
- Promote cognitive development by increased brain function
- Lead participants to explore their environment
- Provide security
- Be an unrestrained atmosphere where participants feel able to enjoy themselves.
- Improve creativity
- Stimulate the sensory building blocks
- Develop a sense of cause and effect
- Develop language – more vocalization
- Promote social interactions
- Promote mental and physical relaxation – Stress levels drop dramatically
- Result in more calmness and lower aggressive behaviours
- Increase opportunity for choice and self-determination
- Improve communication and sharing
- Lead to non-responsive patients becoming communicative
- Provide relief from pain and painful physiotherapy

WHAT IS A MULTI-SENSORY GARDEN?

A multi-sensory garden is a garden environment designed with the purpose of stimulating the senses.

This stimulation occurs through plants and the use of materials that engage one's senses of sight, smell, touch, taste, and sound.

These types of gardens are popular with both children and adults, especially those who have sensory processing issues, including autism and other disabilities.

Recent research on sensory gardens showed promising results for children with developmental disabilities. In one study, researchers attempted to study the influence of a sensory garden on a sample of children with special education needs.

The findings showed a sensory garden provided students with a stimulating experience and positively influenced their behaviour and development in terms of social relationships (Hussain, 2012).

A recent study evaluated the outcomes of outdoor play using a multiple baseline research design. Positive treatment outcomes were seen in a clinical treatment setting (McConkey, 2016).

WHAT DOES THE RESEARCH SAY ABOUT MULTI-SENSORY ENVIRONMENTS AND AUTISM?

Research is scarce on the effectiveness of multi-sensory environments among people with autism and findings are mixed. Two studies found positive results for people on the spectrum.

Research carried out in Brussels attempted a comparative study of the behaviour of nine adults with profound autism in both classroom and multi-sensory room settings.

There were variations in individual results but a 50 per cent reduction in distress and stereotypical behaviour and 75 per cent less aggression and self-injury in the sensory room environment ("Multisensory stimulation", n.d.).

Results of another study showed that multi-sensory intervention was helpful in decreasing disrupting behaviours in individuals with autism (Fava & Strauss, 2010).

Despite its popularity and widespread use, research on the therapeutic effectiveness of multi-sensory environments is limited and the research there is has limitations (Hogg et al, 2001).

For the environments to have beneficial outcomes, an individualised plan should be developed for each client depending on their particular needs and challenges.

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Continued from page 15

We would encourage the student to turn off or put equipment away. Responding to verbal prompts from the facilitator, the student clarifies their goals for transitions back to class. Levels of guidance reduced as time progresses. The intention is that this will lead to greater autonomy and benefit students by increasing their ability to address their needs independently as they grow older.

WHEN IS IT USED?

The use of our sensory room is flexible and focussed on the needs of the individual. We examine patterns of events, triggers and behaviours. Some students struggle with the transition between arriving at school and heading into class. Some students struggle with the transition into the classroom following lunch breaks.

The sensory room may be booked in advance or negotiated when needs arises.

A number of students have used our sensory room regularly. Observations highlighted that the majority of students preferred to control, reduce, or limit the stimuli they were receiving.

SYSTEMS AND MANAGEMENT DEVELOPMENT

I have created two key documents regarding the use of the sensory room. We have a "Procedures Manual" which outlines key procedures, the philosophy, the booking system and equipment. The second document is a "Sensory Room Response Evaluation" sheet used to collect data on the frequency and duration of student use, their preferred set up and their responses to the intervention.

IS THIS INCLUSIVE?

Some may consider this intervention as non-inclusive. Is it possible to provide controlled sensory experiences and still have inclusion within a community?

Fowler (2008) poses an interesting perspective. Being included and controlling one's sensory experiences do not have to oppose each other. Our goal is to meet individual specific needs and to encourage positive transition back into the classroom.

EFFECTIVENESS OF THE INTERVENTION

Reflective practitioners are encouraged to examine practice and critically review the interventions recommended and implemented. Critical revision of Snoezelen and of multi-sensory rooms by Research Autism (2013) and Texas Statewide Leadership for Autism Training (2009) identified that neither of these are an evidence-based intervention and require further research.

A revised edition of New Zealand Autism Spectrum Disorder Guidelines was completed in 2016. Part 3: Education for learners with ASD identifies that a positive strategy of providing a quiet space or area and allowing, "regular, timetabled 'down time'" could have benefits for young people with autism (p.119).

At our school, if a student feels that the classroom does not provide a quiet enough space for them, they have the option of accessing the sensory room as an alternative space.

The autonomy of students is encouraged. We aim to develop students' skills and their ability to manage their personal challenges. The Specialist Service standards refer to the three principles of Te Tiriti o Waitangi, partnership, protection and participation. We have an area that is well thought out, and adaptable. We provide effective, caring, support and guidance. We aim to support and maintain student presence at school.

Heightened states of sensory processing and behaviours because of anxiety, stress and frustration are challenging. We explore the function of behaviours. The student response

evaluation sheets gather data and they identify trends of frequency, preferences and feedback for each student using the sensory room.

This data informs practice. Macfarlane (2003) recommends schools have an opportunity to develop a strong ethic of caring (manaakitanga) and attending to each student, not just for the head but also for the heart as well providing a "safe haven classroom" (p. 97).

I believe our decision to go ahead with a room is supported by Pere's (1991) concepts of holistic well-being: taha tinana, (physical well-being), hinengaro, (the mind), mana ake, (the uniqueness of each individual) and mauri, (life force/energy) within the Maori health model, Te Wheke. The integration of this intervention is student-focussed.

Observable and anecdotal evidence from facilitators, class teachers, parents and students indicated that for numerous students we have been able to address sensory and anxiety concerns and the intention is that we will continue to do so in the future.



Sue Kinnear (B.Ed, P.G.Dip.Sp.Tchg – Autism) is a Special Education Needs Coordinator and a Specialist Teacher of Autism, currently working at an Intermediate in the Greater Wellington district.

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Want sugar with your spaghetti?



French writer Josef Schovanec's biography describes him as an 'activist for autistic people'. "What does that mean?" Altogether Autism editor Mary Anne Gill asked him in Wellington where he is living for five months as the 2017 laureate of the Randell Cottage Residency.

JOSEF SCHOVANEC wanted to become a lecturer in philosophy but instead he travels the world attending conferences, appears on radio and television to shed light on what it means to be a person with autism and writes constantly.

In France, where he was born on 2 December 1981 to Czech parents, he is a media personality.

So what brings him to New Zealand for five months when the bulk of his work is in Europe?

Schovanec is researching a fictional book about an autistic friend's journeys and research in the Pacific, a slight change in direction for the writer, polyglot (a person who knows several languages) and activist whose four other biographical books included the first memoir by an autistic person released by a major French publisher.

Securing a Randell Cottage residency and living in Wellington until June 2017 gives Schovanec something he looks forward to – relief from the thousands of emails he receives about autism.

"I hope it will help me handle my exhaustion too," he says.

This is the first time Schovanec, who speaks several languages including English, has ever lived in an English-speaking country. An impatient publisher back home in France is not making it easy for him to relax though. There are deadlines for the three other books he is writing.

However, he has made a commitment to himself to expand his linguistic skills to include Maori.

"I would like very much to learn Maori. I don't think I will become a fluent speaker but in four to five months, I could get to a nice level," he says modestly.

Writing in Maori appeals to him too. "Maori delivers you from the painful dilemma of having two consonants next to each other."

That journey to learning Maori started on Waitangi Day when he attended the celebrations at the Treaty grounds in Northland and stayed in Russell.

He also added 10 extra pages in his mind to his latest book about autism because of his experiences there.

He describes his social skills as poor and his understanding of certain situations bemusing even though he is clearly a bright man.

"I arrived to the hotel in Russell and there was a very nice gentleman greeted me there. 'Are you here on your own?' and so I said yes. He asked me a second time and I thought he was asking me because I am kind of a hero – from Europe to Russell.

"It's only later I understood because I was dressed like an official and Russell is a holiday resort where you're not supposed to go there on your own.

"I need to change my clothes to the place I am. It's a great skill people have but I don't have."

Schovanec was born in Charenton-le-Pont and has an older sister.

"I felt I was special from the very beginning. The first physicians my parents took me to thought I had a form of schizophrenia. They treated me for that but the medication was not appropriate."

France, and many parts of Europe, were very backward (back then) in their understanding of autism, he says.

"The majority of people with autism in France at that time had this type of negative experience."

Schovanec's parents were both well educated and that made a big difference for him.

Partly home-schooled, he was able to learn maths from his mother because she was an engineer.

Continued page 18



NINE TO NOON: Josef Schovanec with RNZ's Kathryn Ryan.



RESTORED COTTAGE: Wellington's Randell Cottage, Josef Schovanec's home for five months.

Continued from page 17

And by staying at home, he could read the many thousands of books his parents had.

By the age of seven, he could speak fluently in French, Czech, Finnish and English.

In later years, he added German, Hebrew, Sanskrit, Persian, Amharic, Azeri, Azerbaijani and Ethiopian.

"I could attend school but not all the time. School was almost unbearable for me. I could not go to the canteen; I have never eaten at a canteen.

"I was lucky with my parents. Other parents would just break and give up, particularly at that time (late 1980s). Parents were under such big pressure. All the physicians wanted to take your child and put them into a mental facility to cure that child.

"My parents never, ever accepted them. They tried their best to keep me partly at school," he says.

On top of that, his parents had to find a solution for their son's problems with food.

"90 per cent of children with autism have similar difficulties," says Schovanec who goes on to reveal his food of choice for several years was spaghetti with sugar.



"People would think I was crazy. My parents love Italy and speak Italian very well so several times during my childhood they took me to Italy.

"Imagine being in a proper Italian restaurant and you order spaghetti with sugar. I have very vivid memories of some of those episodes. Once I was in a restaurant and one of the employees was begging me to eat something else. I was crying, yelling. I wanted spaghetti with sugar."

He no longer only eats spaghetti with sugar but going to a restaurant is still almost impossible for him.

By his high school years, Schovanec's maths was so good he considered becoming a mathematician but instead graduated from Sciences Po University (Paris Institute of Political Studies), an elite institution whose alumni numbers four French presidents, 13 past or present French prime ministers and the founder of the modern Olympics, Pierre de Coubertin.

His social skills did not improve though and the medication he was on for schizophrenia meant he was sleeping all the time.

It was not until 2007 that he received a diagnosis of Asperger's syndrome and that is when he became involved in autism awareness campaigns becoming a celebrity on radio, television and print.

His first book, the best-selling *Je suis à l'Est!* written in collaboration with Caroline Glorion, was an autobiography, which reflected on the differences between non-autistic people and persons with autism.

Parents of children with autism seek him out relentlessly thinking he has been successful in managing his autism.

Sometimes they say to me 'I am so glad my daughter or son is on the spectrum. I don't have to worry about drugs.

"Actually they are wrong about me, they are mistaken and they usually notice it very quickly because actually I am not successful. I am as backward as their child (is).

"For instance, I cannot drive a car, I've never been to the hairdresser, I've never been to a night club. There are many things that I cannot do. Many people with autism are more skilled than me.

"What I'm trying to do is speak about all my friends.

"99 per cent of the people I meet on the spectrum don't want to talk about autism."

While he does travel a lot, it is something he still finds difficult.

"You learn about the airports and where the good hotels are.





AUTISTIC ADVOCATE: French-born media personality Josef Schovanec feels his social skills are getting better.

I don't mean five stars, good by my standard."

He can write anywhere, never in English, usually in French or German. None of his books has been published in English because he says the English-speaking world is more advanced in the field of autism and there are thousands of books.

The experience in Waitangi and a trip to Cape Reinga gave him many ideas for his books.

"The colours, the different kinds of blues. The spiritual side."

He finds his social skills are getting better but still probably lower than what people expect and believe of him.

"I'm not really good at relationships. I don't have a vibrant social life. I never know what is the definition of a friend. Anyone who is nice to me and smiles and says hello – he or she is a friend but that can lead to great trouble. That's what happened to me in the past. I'm protected in France and in Europe. Nobody in the autistic community would harm me."

Schovanec is adamant there is no link between vaccinations and autism but is unable to come up with a cause.

"I do hope nobody ever finds the cause because we need autistic people. How sad would our universe be without all those great people.

"There are some aspects about autistic life that are not very funny but broadly speaking, it's not that bad," says Schovanec.

The Randell Cottage Writers Trust was established in 2001. The restored 1867 Thorndon Cottage, one of Wellington's 10 oldest buildings, was gifted to the trust by the Price family and hosts two writers a year; one from New Zealand and the other from France. Randell Cottage is supported by Creative New Zealand, Wellington City Council, the New Zealand France Friendship Fund and the French Embassy.



Educational practices



Australian-based education advisor **Emma Goodall** is an educator and autistic. She reflects on autism-friendly practices in education.

GOOD TEACHING does not necessarily meet the needs of autistic students. But good autism-friendly teaching will meet the needs of most, if not all, students in a class. All students have strengths and support needs.

The profile of autistic students is complex with support needs that vary according to both emotional and physical contexts. The strengths of any individual autistic may be obvious or they may take time and patience to uncover.

Autism-friendly educational practices should use an individual's strengths to help them learn new skills and knowledge in ways that minimise anxiety and maximise interest and engagement.

However, it is important to recognise that positive interpersonal relationships between teachers, teacher aides and autistic students are a pre-requisite for high levels of engagement. This can be challenging for adults who are used to particular types of social interactions.

For example, if a teacher is used to greeting their students in the morning with a smile and verbal greeting, this teacher can experience a range of emotions in reaction to a student (whether autistic or not) who does not respond to these greetings, or responds by running away. As an educator and an autistic, I am aware of the difficulties faced by both teachers and autistic students in today's schools and preschools.

However, with a positive, passionate, kind but firm and caring teacher who is willing to teach using the autistic student's interests in a way that broadens and deepens the student's knowledge, autistic students are more likely to enjoy their time in school and achieve more.

The hidden curriculum – all the unspoken norms of school – can be bewildering for autistic students as well as students who are recent arrivals into New Zealand. Autism-friendly practices highlight inclusivity and meet the needs of all students who are unable to notice the socio-cultural norms of the classroom and playground. For example, educators should use explicit explanations, whether visual and/or verbal, to help students understand the roles and responsibilities of all the various groups of people in a school.

Without this, most autistics are unaware that a social hierarchy exists; let alone how to respond to this appropriately. This results in autistic students following instructions given by a peer rather than a teacher, not because they are naughty or obnoxious, but because they genuinely do not know that the teacher's instructions are the ones that they are meant to prioritise.

Finally, some autistic students can manage in modern or open plan learning environments with minimal accommodations, but for others, particularly those with Attention Deficit Hyperactivity Disorder and those with sensitivities to noise, these types of learning environments can be both exhausting and extremely distressing.

Usually this distress will manifest in behaviours that interrupt and affect the learning of not only that student but also other students. Providing a very quiet withdrawal area that students can retreat to whenever they feel the need is vital to facilitating learning for these students in modern or open plan learning environments.

There is some misunderstanding about the ability to cope where autistic students have managed at pre-school and then are unable to manage in a similar environment in a school setting. However, the demands placed on children in pre-school are considerably fewer and of less consistent intensity than demands placed on students in school.

Anxiety in autistic students is not always obvious to educators and presents differently in different students at different times. Autism-friendly education takes into account the sensory profile of students and ensures that the environment is not overly stimulating but still provides engaging and motivating prompts for learning.

Dr Emma Goodall is a published author and lecturer at the University of South Australia (Education Department).

Whenever new research is published, those of us with a special interest in autism check it out with equal parts of enthusiasm and caution. When the University of Auckland published new research in 2016, our national manager Catherine Trezona, asked Liliya John, one of our researchers, to investigate the findings. It seemed zinc might potentially safely support improved brain cell communication, and in the words of the new research 'offer hope of new autism treatment.'

University of Auckland study on autism and zinc



A new study recently published indicates that zinc may impact autism. In this article, we outline the findings but emphasise that there is not yet sufficient evidence to be sure if zinc dietary supplements will affect autism. Further, taking too much zinc is toxic and supplements should not be given to children or taken by adults without medical advice, writes Liliya John.

A JOINT STUDY led by neuroscientists in Auckland, America and Germany has shown cells that carry genetic changes associated with autism can respond to zinc and that zinc can boost the cell communication weakened by autism.

Their research is focused on a protein called SHANK3, which is associated with neuro-developmental conditions such as autism and schizophrenia. The study was published recently in the Journal of Neuroscience, and was funded by Marsden Fund and the neurological foundation (Johnston, 2016).

Auckland University's lead investigator is Associate Professor Johanna Montgomery from the Department of Physiology and Centre for Brain Research.

Her research showed that gene changes in autism decrease brain cell communication ("Zinc found to reverse brain cell changes in autism," 2016). Many of the genes changed in autism involve proteins positioned at the synapse (the boundary region) between nerve cells. Earlier research by Montgomery and Craig Garner, Professor at the University of Stanford, had identified how autism-related changes to a group of proteins called SHANK proteins alter the structure and function of the synapse and that zinc could change the function of these proteins (Morton, 2013).

BACKGROUND INFORMATION ON THE AUTISM AND ZINC CONNECTION

The recent interest in autism and zinc is based on studies indicating that zinc deficiencies may contribute to autism (Faerber, Zinn, Kern & Kingston, 2009). In 2014, Faender and Grabrucker found that more people with autism were lacking in zinc compared with neurotypical control group matched in terms of age. Research also showed that pregnant mothers with zinc deficiencies may increase the likelihood of autism in her children and might also lead to brain impairments later in life (Vela et al., 2015).

Zinc is an essential trace element found in humans and is capable of supporting normal growth and development across various stages of lifespan such as pregnancy, childhood, and adolescence. Zinc is also an important anti-oxidant and is involved in immune system functioning, wound healing, cell division, and senses such as taste and smell (Bjorklund, 2013). As one of the most prevalent metal ions in the brain, zinc has a key role in shaping cognitive development and maintaining healthy brain function through its involvement in various neuro-physiological processes such as the regulation of growth, development and movement of nerve cells, known as neurogenesis, neuronal migration, and differentiation (Vela, Stark, Socha, Sauer, Hagmeyer, & Grabrucker, 2015). Zinc deficiency in humans results in a variety of conditions including growth impairment (Cole & Lifshitz, 2008) and cognitive impairment (Prasad, 2013).

ZINC AND CELL COMMUNICATION

SHANK3 is a protein responsible for facilitating communication between neurons. Changes in the SHANK3 are one of the most common genetic changes associated with autism (Durand et al., 2006).

According to Montgomery, lead investigator of the study at the University of Auckland, current research shows that even where the SHANK3 gene is changed in people with autism, the gene is still responsive to zinc. The SHANK3 gene is capable of acting as a zinc sensor at the synapses, and also can enhance the communication between the brain cells. So even though the SHANK3 gene is changed, these changes do not take away zinc's ability to strengthen and stabilise synapses (Johnston, 2016). Montgomery's current research has shown that zinc can increase brain cell communication that was previously weakened by autism-associated changes in SHANK3 (Arons et al., 2016).

IS IT SAFE TO TAKE ZINC SUPPLEMENTS?

The findings are promising as they offer the possibility that zinc may be considered for treating autism in the future. The researchers are now making further plans to investigate whether dietary zinc supplements can be used to improve brain cell communication resulting in improvement for the autistic person. Montgomery warns that too much zinc can be toxic and emphasises the need for determining the optimum levels of zinc that can be safely consumed. Future research aims to determine whether zinc is beneficial for all or a just for some autistic people ("Zinc offers hope of new autism treatment: Study", 2016).

ABOUT THE AUTHOR:

Liliya John MSc, PG Diploma (Psych) is a researcher for Altogether Autism.

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However, when Catherine shared the findings with Paula Jessop, member of our consumer reference group, Paula recommended caution in publishing the research report. Here, we share both Liliya's research report and Paula's cautions, as we try to balance reporting potentially helpful research while guarding against making premature conclusions that might be harmful.

Research of no practical use to families



Paula Jessop is a member of the consumer reference group for Altogether Autism. She warns about the dangers of false hope that research in early stages gives. Paula is concerned not only by the risks to autistic people, particularly children, associated with unnecessary and unproven treatments, but also the negative effects of underlying assumptions about the need to cure autism.

RECENT RESEARCH about the impact of zinc is in the very early stages and does not necessarily tell us much other than zinc is somehow playing a part in autism at a gene/brain cell level – to use nonprofessional's language.

At present the research is not of practical use to autistic people or their families.

RISK OF PHYSICAL HARM

Parents who are desperate for some cure or treatment could ignore warnings that zinc supplements can be harmful. As we already know, many parents are already putting their children on a number of supplements without any real knowledge of the potential harm in doing so in the hope that 'anything is worth a try'.

There have already been some cases internationally of children becoming physically sick because parents were unaware that the high doses and large quantities of vitamin, mineral and 'natural' supplements given to children could have dangerous adverse impact on their children's health.

WHY IS AUTISM SOMETHING THAT NEEDS TO BE CURED?

Talking about autism in this very general sense is also dangerous in my opinion. It is not just the language; it is the attitude or perspective underlying the language and the assumption that any new information, which might help unravel the underlying, causes of autism is good because it might lead to some form of treatment that can fix some part of autism.

We know that autism manifests differently in every individual, and is accompanied by a host of variable traits and potential co-occurring conditions. So how can it be at all useful to discuss autism in such a generalised manner?

The research could potentially be useful once more studies have been conducted and when we know more about how zinc affects specific aspects of autism.

It may be the case that this gene/brain cell issue may be contributing to immunity issues or physical issues such as wound healing. It may play some part in difficulty with learning and using language, or learning disabilities in general. When the research gets to the point of being more able to clearly pin point specific issues, then it may be useful.

But, there's also a chance that what we'll discover is only minimally helpful. We already know, within autism communities, that there is some issue with our bodies and zinc due to our experiences of having doctors tell us our levels of zinc remain well below normal, even when we take zinc supplements to correct it.

What we also know from anecdotal evidence is that generally we don't experience any real change to our autism if we do manage to increase the levels of zinc in our body.

We do know that some people find they get sick less often and that skin wounds heal more quickly.

We also suspect that whatever our problem is with zinc may well have some contribution to co-occurring physical issues we have such as high levels of autoimmune problems or tendencies to get sick more often and for longer.

With all this in mind, neither the current research nor our anecdotal stories actually tells us much more than zinc is somehow related to autism.

Therefore, until such time as the connection is better understood, I think in some ways it's irresponsible to raise false hope or risk influencing parents to give kids more supplements unnecessarily and with possibly as much risk to their health than clear potential for gain.

I believe we autistic advocates, organisations such as Altogether Autism and professionals working in the field have a moral and ethical responsibility to think more critically about the potential negative effects on autistic people of research in the very early stages, which is not yet giving us enough information for real benefit.

We need to go beyond having a rather superficial understanding of the impact of language where autism is described in such a general sense and continues to be portrayed as a condition which is so bad that every possible little thing which might treat it is good.

We need to all be asking the questions: 'which aspects of autism actually need treating' and 'which aspects of autism need support' for autistic people to thrive in the world.

Until people start thinking of autism in this way, the view that ALL of autism is bad will predominate – and that is not helpful for autistic people.



Study shows exercise improves quality of life for children with autism

NEW RESEARCH has found that regular exercise improves communication behaviours among children with autism.

The findings are the result of a four-month collaborative study between researchers from Achilles International and the New York Medical College, funded by the Cigna Foundation in America.

The study measured the effect of the Achilles Kids running programme, with 94 students with autism across five schools taking part. It assessed restrictive and repetitive behaviours, social interaction and communication, emotional response and cognitive style. The research found that regular exercise helped improve the students overall quality of life – helping them engage in everyday social situations, reducing their anxiety and in turn improving their peers acceptance and inclusion.



"The results are extremely encouraging as millions of parents, caregivers and medical professionals grapple with how to best support children on the autism spectrum," says Jo Walker, Chair of Achilles New Zealand.

Wellington mother Elizabeth Abbey can further validate the findings. Her son Ethan, who has Asperger's syndrome, runs with Achilles.

Jo Walker

"Exercise has been an integral part of Ethan's life. We were adamant that his disability wouldn't impact on his quality of life and from a young age we made sure he was very active, regularly running, swimming and hiking.

"As he got older we noticed that after a run he was calmer, less anxious and more lucid in his conversation. He even said he felt better," says Elizabeth.

Following the death of Ethan's father last year Elizabeth knew she needed to keep him running. Alongside other networks Ethan is involved with Achilles seemed tailor made for their needs.

"The fortnightly runs fulfil much of the role his father did – the guides are young, active and like-minded and offer a community and support network that enables Ethan to run longer distances regularly which really help him."

The support offered by Achilles meant that Ethan was able to take part in this year's Cigna Round the Bays – an event he has taken part in every year since he first ran it with his father in 1991.



Catherine Trezona

Altogether Autism national manager Catherine Trezona says it was encouraging to see the positive impact of exercise upon overall quality of life.

"In keeping with previous research, this study has demonstrated that physical exercise can bring a range of benefits for children with autism. We expect to see physical advantages from exercise, but the reduction in anxiety and improved social inclusion is perhaps a surprising but no less important benefit for children on the spectrum."

In America, the Achilles Kids school-based running curriculum helps adaptive physical education teachers—whose students include children with autism—implement a running-based program in their schools. The students are given the goal of running 26.2 miles—the marathon distance—in a school year.

The school-based study was funded by World of Difference grants given to Achilles in 2014 and 2015 by long-time partner Cigna Foundation. Existing literature on this topic often examined small sample sizes or community-based programmes, and so the Achilles and NYMC teams sought to quantify extensive anecdotal evidence observed by Achilles showing physical, social, emotional and academic improvement in children with autism spectrum disorder who regularly ran with their program as part of their school day.

The study was released late last year at the Academy of Paediatric Physical Therapy's Section on Paediatrics Annual Conference (SoPAC).



ROUND THE BAYS: Ethan Abbey runs with Achilles. Picture courtesy Achilles Wellington

Spectrum-friendly Permian monsters

Waikato Museum is offering people with autism the chance to enjoy their next exhibition in a comfortable and accepting environment. In March 2016, Daniel Smith, member of our Consumer Reference Group, met with Public Programmes co-ordinator Kirsten Peterson, to develop *Da Vinci Mechanics*, the museum's first autism-friendly exhibition. One of the changes the museum made on Daniel's advice was to label each exhibit with green or red, making the interactive exhibits clear. Find out about the modifications the museum will make to the environment for their **Life Before the Dinosaurs** exhibition.

WAIKATO MUSEUM'S upcoming exhibition transports you back in time 290 million years when bizarre-looking animals dominated life on land and sea.

Permian Monsters: Life Before the Dinosaurs brings the past back to life with fossilised skeletons and full-size life models of the animals that ruled the world millions of years before the age of dinosaurs, in a time known as the Permian.

The Permian period ended with the largest extinction Earth ever experienced, which wiped out 90 per cent of all species on the planet. The cause of the end-Permian extinction had baffled scientists for the past 20 years but a recent discovery shed new light on the cause of this catastrophe: global warming. Find out how this familiar phenomenon, started by a huge volcanic eruption, set off a chain of events that led to the greatest extinction on Earth.

The exhibition blends art and science with a collection of new artwork, which offers a glimpse back in time through the eyes of award winning paleo-artist Julius Csotonyi. View fossilised skeletons and reconstructed models of these amazing but bizarre creatures that dominated land and sea; and dig and identify fossils in the interactive dig pits throughout the exhibition. Meet giant insects, strange reptiles with mammal-like characteristics and the top predator of the time, the giant sabertoothed gorgonopsid *Inostrancevia*.

The exhibition runs from 13 May – 13 August 2017. Waikato Museum is offering people on the spectrum the chance to enjoy *Permian Monsters* in a comfortable and accepting environment on Saturday 3 June from 6pm to 8pm.

Modifications to the exhibition will include a less crowded environment, light and sound reduction and extra visual signage.





The science facts about **AUTISM AND VACCINES**

WHAT STARTED THE RUMOURS?



1998



Lancet published a paper by Dr. Andrew Wakefield, a dramatic study that found a connection between autism and vaccines

The Study Had Some Problems



Not based
on statistics



No control
group



It relied on
people's
memories



Made vague
conclusions
that weren't
statistically valid

NO LINK WAS FOUND

So people started investigating his claims

1999

a study of
500 CHILDREN
no connection was found

Following Dr.
Wakefield's study,
here's what other
more rigorous
studies found

2001

a study of
10,000 CHILDREN
still found no connection

2002

a study from Denmark of
537,000 CHILDREN
found no connection

a study from Finland of
535,000 CHILDREN
once again found no connection

2012

A review of 27 cohort studies,
17 case control studies, 6 self-
controlled case series studies,
5 time series trials, 2 ecological
studies, 1 case cross-over
trial covering over
**14,700,000
CHILDREN**

2005

A review of 31 studies
covering more than
**10,000,000
CHILDREN**
Also found no
connection

2004

Lancet released a
statement **REFUTING**
the original findings

**NO LINK TO AUTISM WAS
FOUND IN ANY CASE, IN
ALL OF THE STUDIES.**

“ They had conducted invasive
investigations on the children without
obtaining the necessary ethical clearances...
picked and chose data that suited their case;
THEY FALSIFIED FACTS. ”