

ALTOGETHER AUTISM
JOURNAL
ISSUE 2 2016

**DUNGEON
MASTER:
Breaking
the label**

**Autism in
the workplace**

**The disclosure
dilemma**

ALTOGETHER
AUTISM



ALTOGETHER AUTISM

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 officers and researchers. Our 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 expertise in autism.

Whether you are on the autism spectrum or you are family/whānau or a professional supporting an autistic person, our service is free. Contact us at any one of the following links:



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0800 273 463

UC researchers study how children with autism sleep

Two University of Canterbury (UC) researchers are seeking participants nationwide for a study into the effectiveness of treatments for sleep disturbance in children with autism.

UC School of Health Sciences senior lecturer Dr Laurie McLay and Associate Professor Karyn France are keen to provide assistance to families of children with autism as part of the research process, and say help is available for children across the range of communicative ability.

"Sleep is one of the major concerns reported by parents of children with autism. Our study offers practical support to families, who select an individualised treatment to use with their child to improve sleep," Dr McLay says.

Participants can be based anywhere in New Zealand and can include children across the autism spectrum who have sleep disturbance and are not currently receiving treatment for it. Children should be aged three years or older, and have a formal autism diagnosis.

Dr McLay says there are very high rates of sleep disturbance in children with autism and problems can develop due to physiological components, as well as environmental influences.

"As many as 40 to 80 percent of children with autism have some type of sleep difficulty. This can include delayed sleep onset, frequent and prolonged night awakenings – or a combination of both," she says.

"Sleep disturbance can have an impact on a child's learning, behaviour and socialisation, as well as affecting the overall wellbeing of parents, who can become stressed and also affected by lack of sleep."

The study is supported by a research grant from the IHC Foundation and the UC researchers have been working in partnership with IDEA Services and various autism support networks to recruit participants. The research team has already worked with a number of families to successfully reduce sleep problems.

"We've had a good response in Auckland and Christchurch, but there is room for more children in the study right around the country," Dr McLay says.

Information about children's sleep behaviour will be gathered using sleep diary and video recordings, after which the research team will support parents to implement the chosen treatment option.

"It's all about parental choice. Treatment options are individualised based upon the needs of each child. The family then chooses the approach they want to try and we will work with them until they are satisfied that the sleep problem is alleviated, or until they decide they want to withdraw from the study."

The study focuses on behaviour therapies and other treatments such as the use of white noise and massage therapy. Dr McLay says this study is about investigating the effectiveness of approaches that may minimise parent and child distress.

The researchers are based in the Pukemanu – Dovedale Centre, a teaching clinic run by the University of Canterbury's Child and Family Psychology programme. Families outside Christchurch are catered for by visits to home towns and local research assistants.

Dr McLay teaches courses in specialist teaching at UC, where she completed her PhD working with children with autism. Associate Professor France is a qualified clinical psychologist who has spent many years working in the area of child and family psychology, with a strong research focus within the Canterbury Sleep Programme on child sleep behaviour.

**To participate, contact Dr McLay:
Phone 64 (3) 364-2987 ext. 7176
Email laurie.mclay@canterbury.ac.nz**



Networking, training and transitioning



In this issue we consider employment for people with autism, looking at the strengths and challenges. Research and experience points to autism being a barrier to employment, and once employed, people on the spectrum are often over-qualified and under-paid. But there is an emerging trend of employers recognising the strengths of autism in the workplace. We hope that more New Zealand employers will see the advantages of people with autism in their workplaces.

In the past three months we have been busy with *Prism*, our autism training for professionals. These workshops have been very well received in Whangarei, Auckland, Hamilton, Tokoroa, Christchurch and Nelson, with Palmerston North and Levin and Lower Hutt bookings in June. Please contact us if you would like to discuss bringing this popular and effective training to your organisation.

I have also been travelling throughout New Zealand with our network meetings, sharing how Altogether Autism is *Your Doorway to a World of Support*. By the time you read this, we will have had meetings in Tauranga, Whangarei, Kerikeri, Christchurch, Dunedin, Cromwell and Invercargill. In June, we are in Greymouth, Upper Hutt and Porirua. The Waikato meeting is on August 11, and Taupo, we are coming to you on September 1. Please see our back cover for details of venues and times for upcoming meetings.

These network meetings are being enriched by presentations from members of our Consumer Reference Group and from the wider autism community. Paula Jessop spoke at the Tauranga meeting and John Greally will be speaking in Wellington. In May, Nick Stoneman and Beth Freeman spoke on their personal journeys with Asperger's and what it means for them in real life in Christchurch. At the end of May, Tanea Paterson shared her lived experience with a powerful presentation at the network meetings in Dunedin, Cromwell and Invercargill.

At these meetings, we also present a one-hour *Prism* workshop, with a focus on autism, mental health and wellbeing. A focus on mental health is also the theme of our next *Journal*, so if you would like to contribute to that edition, please contact us by email, website or Facebook. The deadline for submissions is July 1.

Thank you to the 129 people who completed our online reader survey after our last edition of the *Journal*. We received encouraging feedback letting us know it is well-read and appreciated. Overall your responses confirmed that our balance between lived experience, professional advice and research is about right for most of you. The \$100 Prezzie Card winner has received this reward. Several people suggested we add a Letters to the Editor section and we are keen to do this, so watch this space.

Catherine Trezona

National Manager, Altogether Autism

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SAVE THE DATE

Altogether Autism 2017 Conference

July 19-20, 2017
Holiday Inn Auckland Airport

Welcome to the team Daniel

We are delighted to introduce Altogether Autism's newest member of the Consumer Reference Group. DANIEL SMITH is a hard-working father and partner. Altogether Autism researcher TEGAN ANDREWS talks with Daniel and his partner Rebecca to find out more about him and his experience with autism.

How would you describe yourself?

I am a father to five children and live with my partner and her three children in Te Aroha. We enjoy being a family and our best times are spent together. We support and encourage each other to be the best that we can be and to help others where we can.

What is your relationship with autism?

I am on the autism spectrum and four of my five children are also diagnosed on the spectrum. My partner has two children in her care diagnosed on the spectrum.

What sorts of things do you do and enjoy doing?

I am a technical specialist in Immunohistochemistry for Waikato DHB and work full-time. Outside of work I enjoy time with my family, and like gaming (computers/consoles and board) with them, films (cinema and home), and science fiction (especially *Star Wars*).

How did you first hear about Altogether Autism?

I first heard of Altogether Autism when my children were assessed by the Child Development Centre at Waikato Hospital. I became more involved with Altogether Autism when I was assessed as an adult by Tanya Breen (I was diagnosed in the UK as a child, but never told), and was then asked to present at the Altogether Autism Conference last year.

What prompted you to join our Consumer Reference Group?

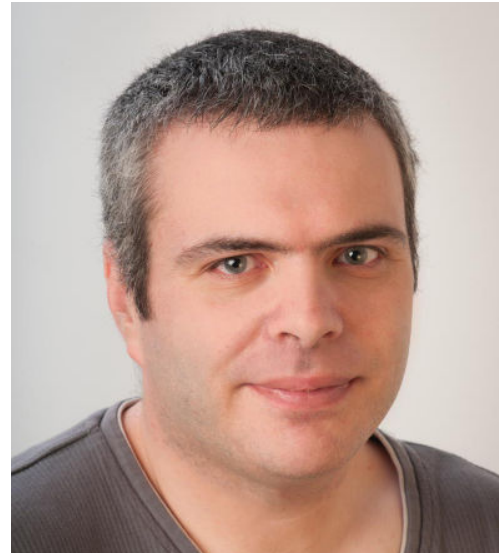
With six children in the household on the spectrum, I wanted to do more to advocate for them and, after discussing with several people, found that I could be of help to others by my lived experience.

Are you involved in the autism community in other ways?

I have started a Facebook page called Autie/Aspie Waikato where I'm hoping to bring the autism community in the Waikato together for different events and get to know each other. I've had the privilege of working with the Waikato Museum to help with its Autism Awareness Day opening, and have been asked to present at different meetings on autism.

What Rebecca had to say:

Daniel and I have been together for nearly four years. He's a quiet, honest, very humble, empathetic and trustworthy man



Altogether Autism's Consumer Reference Group member Daniel Smith. Photo: TREFOR WARD

who absolutely loves his kids. Family is very important. Daniel will always go above and beyond to help out people who are in need, be it strangers or people he knows. His mind and ideas and ability to think outside of the square are amazing – there's never a dull moment and he can always make me laugh with his keen sense of humour.

He's taught me so many things – one being that anything is possible. He has a drive to make sure things are done right, which has been an amazing asset when it's come to handling issues within work at times, and also the kids' needs at school, where he's needed to advocate to make sure their needs are met. This has meant meetings with multiple people and organisations at times. As Daniel has already stated, both he and I have kids on the spectrum and his knowledge and experience with autism has been invaluable. He is not afraid to voice his opinions when he needs to. I believe that he will be a valuable person to have on your team.

We think so too! Welcome to the team Daniel.

Altogether Autism has two reference groups we call on for their expertise regarding our more complex requests. Our Consumer Reference Group is made up of people with autism, and parents and caregivers of people of all ages on the spectrum. Each member can provide input from their valuable first-hand knowledge and experience with autism. Our Professional Experts Group is our other reference group, made up of professionals from a range of disciplines and occupations including psychologists, occupational therapists, lawyers, paediatricians, speech and language therapists, and our very own in-house researchers.

Museum tailors exhibition to be sensory friendly

The innovative sensory friendly treatment of Waikato Museum's *Da Vinci Mechanics* exhibition is the beginning of a move to widen the appeal and accessibility of its major exhibitions.



By GEOFF LEWIS

In early April a group of 37 people associated with the autistic community enjoyed an evening showing of the inventions of the Florentine genius which was specially tailored to meet their needs.

Behind the initiative was Waikato Museum public programmes co-ordinator Kirsten Petersen who drew the idea from family experience with autism and her previous work at the Govett-Brewster Art Gallery in New Plymouth.

"We were always looking for ways to improve, and if we found ways we could tweak a show to engage sections of the community that might not otherwise enjoy what we had to offer, then we'd do that."

Kirsten contacted Altogether Autism national manager Catherine Trezona who was excited at this initiative to cater to people with autism.

"Although it is a growing trend overseas, the sensory-friendly *Da Vinci* exhibition was a first for us. We were doubly excited to ask Daniel Smith, who is a new member of our Consumer Reference Group, to help Kirsten," Catherine said.

Daniel, who has Asperger's, checked out the exhibition and made several suggestions around lighting, sound and the use of green and red stickers to indicate which exhibits could be handled, which would make it more appealing to people on the autism spectrum.

Waikato Museum partnerships and communications manager Louise Belay, said the museum had received a very positive response from the autistic community and coming exhibitions later this year – as well as next year's blockbuster *Permian Monsters* exhibition could also be reconfigured to attract a wider audience. The minor alterations made to the *Da Vinci* exhibition to cater to the needs of people with autism, also improved the experience for the general public, Louise said.

Geoff Lewis has been a journalist for 25 years with *Hamilton Press*, *Waikato Times* and *Motortimes*. He now works as a freelance writer for various Waikato organisations and publications.



Waikato Museum public programmes co-ordinator Kirsten Petersen with sensory friendly advisor Daniel Smith.

Photo: GEOFF LEWIS

The strengths of autism in the workplace

Finding a job and maintaining a career can be a challenge for many autistic people, but some employers are starting to see the advantages of having a more diverse workforce.

By CATHERINE TREZONA

For people on the autism spectrum, finding work after leaving school can be hard. Lack of support and the attitude of employers are two of the most common barriers, and in New Zealand most people with autism are under-employed or unemployed, according to the Living Guideline Group Report (2012) on supported employment services. There are some signals that attitudes are changing in particular with large international companies that value the specific skills of some people with autism.

International opportunities

Throughout the world, savvy employers such as Specialisterne in Denmark see the specialist skills of people on the autism spectrum as a competitive advantage. Specialisterne is owned by the Specialist People Foundation and aims to enable one million jobs for people with autism and similar challenges through social entrepreneurship, corporate sector engagement and a global change in mindset. Most people working at Specialisterne are on the autism spectrum.

Perhaps the best known employer of people with autism is Microsoft. Its corporate vice president Mary Ellen Smith, who has a son with autism, announced a new initiative for hiring people on the spectrum on 1 April 2015 before representatives of 193 countries at the United Nations Headquarters in New York City. Smith's position is that "there are unique minds being underused and overlooked" (Microsoftcom, 2016). By February 2016, 11 new employees with autism had been hired and Microsoft is actively seeking more recruits.

Lesser known companies benefitting from their understanding of a workforce with autistic strengths include Passwerk in Belgium, which employs autistic consultants with specialist software testing skills. Electronics and industrial conglomerate Siemens reports its autistic software testers process 50 percent more than their non-autistic consultants. Many autistic soldiers have been recruited by the Israel Defense Forces into Unit 9900, a selective intelligence unit which utilises their heightened perceptual skills.

The cosmetic giant L'Oréal has hired adults with autism to pack products and update databases.

In May 2016, Ford Motor Company announced a new pilot programme to provide training for autistic people. Five new product development positions have been created by FordInclusiveWorks, in partnership with Autism Alliance of Michigan.

In addition, an internship programme set up by the National Association for Parents of Autistic Children in 2011 saw two interns offered full-time contracts due to their professionalism, one as an accountant and the other as a primary resource manager.

What about New Zealand?

While New Zealand cannot boast of initiatives on such large scale, Canterbury pilot employment scheme Project 3000 was launched in April 2015 by the Honourable Nicky Wagner, Minister for Disability Issues. Her intention was to take advantage of the Christchurch rebuild and low unemployment rate to get people with disabilities and health conditions into employment. Case managers from Work and Income work directly with employers to ensure a good fit between the worker and the job. Hon Wagner was pleased to report that by April 2016, over 255 clients had full-time employment, 67 had part-time work and 159 employers had committed to providing vacancies (Parliament NZ, 2016).

The 2012 Living Guideline Group Report on supported employment services found that most people with autism in New Zealand were unemployed or underemployed, including those with post-secondary education. This report notes some practical strategies employers can adopt to create a successful work environment for people with autism. These strategies included matching an individual's strengths, interests and preferences with the job; raising awareness of any support needs a worker may have with supervisors and co-workers; training of job tasks, acclimatisation to the job site; developing communication and interpersonal skills and ways to cope with stress; and using a job coach and workplace modifications where necessary. However, the reality for many people on the spectrum in New Zealand is long-term unemployment. The gap between possibility and reality remains frustratingly wide.



Who can help?

Despite the challenges, those working to support young people to get work emphasise the potential benefits of hiring people on the spectrum.

In her role as service manager at Enrich+ Spectrum Energy, Amanda Phillips supports young people with autism to reach their employment goals in the Waikato.

"Supporting people on the spectrum to find employment is about focusing on a person's strengths and helping them to find an avenue for these," she says. "There are challenges, but the rewards it brings far outweigh these. It is amazing to watch people flourish once they have found the place they fit."

Her advice to potential employers is to consider the strengths and not just the accommodations, as she explains: "People with autism bring so many strengths to a workplace – focus, alternative problem-solving, intelligence, honesty, reliability and a sense of humour. Any accommodations they might need in a work setting are minor. All they need is some patience and understanding as any new employee would."

There are organisations throughout New Zealand that provide employment support. The New Zealand Disability Support Network (NZDSN) has a register of nationwide organisations, found by searching the directory and entering Employment Support in the Services provided field. See www.nzdsn.org.nz/directory.

We have also included some top tips for gaining meaningful employment on page 11.

Valued employees

Once hired, people with autism are gaining a reputation for being highly desirable employees. Employers are reporting that autistic workers are loyal and reliable. A preference for routine makes sick days or resignations less likely than with neurotypical¹ staff.

At Altogether Autism, we often hear that if a strategy is good for someone with autism, it will be good for everyone. This is true in the workplace. Employers are finding that clear instructions and calm sensory environments benefit their general workforce.

Catherine Trezona is the national manager of Altogether Autism

¹ Neurotypical is a term widely used by the autism community to describe those who are not on the autism spectrum

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Your guide to employment rights and responsibilities

Barrister and solicitor NAN JENSEN, who has a special interest in disability law, has put together the below information on workplace law in New Zealand, which is guided by the Employment Relations Act 2000.

Good faith employment relations

The main object of the law is “To build productive employment relationships through the promotion of good faith in all aspects of the employment environment and of the employment relationship”.

The guiding principle is the concept of ‘good faith employment relations’.

So what does this mean? The Act describes ‘implied mutual obligations of trust and confidence’, but says that good faith is more than that. It is about actively maintaining ‘a productive employment relationship’, and that the parties are ‘responsive and communicative’.

Types of employment

There are several types of employment – the three main ones are casual, permanent and fixed term.

- Casual – employee works on an as-needed basis. Holiday pay is paid with wages if work is irregular.
- Permanent – this can be part-time or full-time.
- Fixed term – employment for a fixed period, then the employment ends. There must be a genuine reason why it is fixed term, and the length of time must be specified.

What is and isn’t employment?

The following types of work are not employment:

- Independent contractor
- Volunteer
- Self-employed

- Sharemilker
- A person engaged in film production work as an actor, voice-over actor, stand-in, body double and more
- A person engaged in film production work in any other capacity.

Some minimum rights

There are a number of minimum rights that employees have.

- Annual leave – employees can ask in writing to cash in up to one week of annual holidays per year. Employers may not pressure employees to do this. You can be required to take annual holidays during a closedown period for the workplace, but must be given at least 14 days’ notice.
- Break entitlements – entitlement to rest and meal breaks, which allow reasonable time to refresh and take care of personal matters. No rules for how long these should be – bargaining about these should take place in good faith. Rest breaks should be paid by employer, but there is no requirement for employer to pay for meal breaks.
- Employment agreement (in writing) – this is a requirement. This may be an individual agreement or a collective one.
- Health and safety – employers must provide a safe workplace with proper training, supervision and equipment. Employees may refuse work likely to cause them serious harm. The new Health and Safety legislation (the Health and Safety at Work Act 2015) increases the penalties for situations where workplaces have not met these standards.
- Minimum wage – this is for over 16s only, unless training or starting out, then there is a starting out minimum wage rate. Trainees over 20 must be paid at least the training minimum wage rate.

- Public holidays – there is an entitlement to 11 public holidays off work with pay if these are days where the employee would normally work. If an employee works on a public holiday they are entitled to time-and-a-half-pay. If it is a day they would normally work, then they are also entitled to an alternative paid holiday.
- Right to request flexible work arrangements.
- Equal pay and equal rights.

Employment Agreement

This must be in writing. If there is no written agreement, you are still protected by the Act but, of course, it is harder to prove what was agreed. You have the right to raise a personal grievance at any time, but there is no 90-day trial period.

The following things must be included in an employment agreement:

- Names
- Work
- Place of work
- Hours
- Pay
- How to resolve problems
- Public holiday pay
- Arrangements in the event of restructuring.

90-day trial period

Employers can make an offer of employment that includes a trial period of up to 90 days. This must be agreed in writing, negotiated in good faith and must be signed prior to starting work.

Trial periods are voluntary!

An employee dismissed before the end of a trial period can't raise a personal grievance on the grounds of unjustified dismissal, but can raise a grievance on other grounds such as discrimination, harassment or unjustified action by the employer. The employee is entitled to all other minimum employment rights.

To disclose or not to disclose

The Human Rights Act 1993 prohibits discrimination in employment on the basis of disability, and the Employment Relations Act 2000 contains a duty to act in good faith.

So do you have a duty to disclose that you have a disability that may be hidden? This is a difficult question. On the one hand, there is no duty to disclose if the disability will not prevent you from carrying out the work satisfactorily. On the other hand, there is an obligation to act in good faith.

An employer should ensure applicants are aware of the requirements for the job. They may ask whether there are

medical or physical conditions or disabilities that might prevent them from carrying out the work to a reasonable standard.

They may not ask questions that could indicate an intention to discriminate. If you have not answered truthfully then you can be dismissed – as you were not acting in good faith.

The Human Rights Act includes a concept called reasonable accommodation, which means that the workplace should make changes in order to ensure equal employment opportunities. The test is whether these changes can be made with minimal expense and disruption.

In general, if the best applicant for the job has a disability that requires modification to the workplace or work practices so that the person can perform the role, then the employer should make those modifications.

Minimum wage exemption

The Minimum Wage Act 1983 provides for an employer to be able to apply to a Labour Inspector for an exemption period if the employer and employee agree there is a good reason why the employee should be paid less than the minimum wage.

The Labour Inspector's role is to ensure that the disability really stops you from earning the minimum wage, that you have had someone with you to discuss wages with your employer, and your written employment agreement meets the minimum standards.

The Labour Inspector will issue the exemption permit if the situation meets all other requirements and they are sure that the wage is fair and that you agree to it.

Anecdotal evidence seems to imply that these exemptions are only given for 'sheltered workshops' (workplaces that exist to employ disabled people) and not in individual cases, although this is not how the exemption is described in law.

Solving employment problems

If there is a problem, both parties must try to resolve the issue in good faith.

If that does not work, the employee can raise a personal grievance. This will go to mediation through the Ministry of Business, Innovation and Employment.

If mediation doesn't get a resolution, you can apply to the Employment Relations Authority for an investigative hearing where the authority member will make a determination.

An appeal can be made to the Employment Court – appeals can be made only on points of law or errors of fact.

The Human Rights Commission deals with issues of discrimination.

Who can help?

Auckland Disability Law
www.aucklanddisabilitylaw.org.nz

A lawyer
Look for a specialist in employment law

Your local Community Law Centre
www.communitylaw.org.nz

Ministry of Business, Innovation and Employment
www.mbie.govt.nz

Human Rights Commission
www.hrc.co.nz

Youthlaw Aotearoa
(if you are under 25)
www.youthlaw.co.nz

The reality of employment – from a parent's point of view



By NAN JENSEN

Knowing the basics and what your rights are is not always enough. I have four children, two on the autism spectrum, who have had a variety of experiences in seeking and retaining employment. Here are examples:

- 1) My older son with ASD spent about nine months volunteering through Volunteering Waikato until he found employment close to where we live. This was seasonal employment so it ended. His next job I found through a contact – he has been there five years.

On one hand it is wonderful he has a job. On the other, he is still partially reliant on a benefit, and does not get KiwiSaver as the employer is not obliged to provide this for casual workers. There was a two-week period where he lost his phone and had not informed his workplace. When they could not contact him they eventually contacted me – in an ordinary situation he might have been considered to have abandoned work – so it helped that they knew about his disability and knew me.

- 2) Our daughter, who does not have a disability, got her first job at her first interview at age 15 for a Christmas casual role with a well-known clothing chain. I was concerned about the lack of a written employment agreement and that she did not get paid for the training given, but I knew if she questioned it she may not get shifts.

She was unable to make plans for the week until she received a text Sunday evening letting her know her shift. While she had been led to expect a lot of work, it turned out to be 4-8 hours a week and some weeks no hours. After the holiday she had no desire to work there again.

- 3) Our 17-year-old son with ASD has been looking for work for a long time, and has had a number of interviews. While I encourage him to disclose his disability, his twin sister feels it will lead to discrimination against him. Obviously, we do not know why his interviews have been unsuccessful, but we believe it is because people sense he is different and don't know why. I think disclosure could help, but he does not want to do it. I suspect looking outside the traditional sources of employment may be the answer for him.

- 4) Our oldest son, who does not have ASD, is a bookish kid, not your usual cool dude. He started doing surveys through a temp agency. When the Christchurch earthquake hit and IRD moved its processing to Hamilton, he got temp work there. Later his boss at IRD hired him directly. He wound up spending over a year there and saved up enough to go to the University of Auckland – with his track record he has been able to find temp work through the agency there.

The bottom line is that finding and keeping employment is not easy for anyone at present, so having a disability can make it that much more difficult. For employers, taking someone on is a big risk, and they perceive that many of the laws work against them.

- It helps to have contacts. An employer would rather know the person they are hiring, or at least know something about them, rather than hiring a complete stranger.
- People interviewing will inadvertently look for people like themselves. It is a rare employer who celebrates diversity. Big companies need to hire disabled people as part of the law – so use that! Smaller employers will vary depending on their personal experience and attitude.
- Identify your ASD relative's strengths, then think outside the square to find work that suits them. Customer contact roles may not be suitable. There are many, many other jobs out there.
- Contracting, or self-employment, is not necessarily a bad thing. Maybe their skill or interest can be developed into a small business.



Top tips for gaining meaningful employment

The first step is Transition Planning

- Start planning for the transition from school at the start of high school
- Create a support network
- Make a list of strengths and interests
- Work out what skills/study is needed to get a starting job in your chosen area
- Identify potential barriers and think about solutions
- Seek outside support if needed, including a mentor

Check that all the necessary skills are in place

- Learn skills if needed (i.e. specific classes in school, or a course at tertiary level)
- Make sure you have a morning routine
- Check your personal hygiene
- Practice your time management skills (i.e. getting to work on time)
- Organise transportation to and from work
- Get used to following instructions
- If you suffer from stress or anxiety, have a plan in place to deal with this at work
- Learn about respect for authority/management in the workplace
- Be able to ask for help
- Be prepared to handle your finances

Many people with autism have strengths that are valuable to an employer, so make the most of these if they apply to you.

- Attention to detail
- Good long-term memory
- Enjoying repetitive tasks
- Logical thinking
- May have a specialised area of expertise
- Honesty
- Loyalty

Potential barriers which might hinder employment. Try to be aware of any of these that could affect your role. If so, be prepared with good solutions that could help you e.g. working flexi-hours:

- Employer's perceptions and understanding of autism
- Trouble with social interactions and communication
- Difficulty processing information or instructions
- It may take longer to complete a task
- Difficulties multitasking or switching between tasks
- Time management skills (prioritising and organising tasks)
- Sensory issues (bright lights, office noises) which may also mean a need for more breaks
- Anxiety or other mental health issues

Outside support

There are lots of agencies dedicated to helping people with autism get into employment. Often these can help with everything from a skills assessment and figuring out what type of work may be best for you, to how to apply for jobs, CV and cover letter help and interview strategies.

Applying for a job

CV and cover letter strategies

- Someone from your support network may be able to help with writing a CV and or cover letter
- Follow a template for CV and cover letter – there are many available online

Interview strategies

- Role play the interview
- Scripts – though try not to rote learn these as the questions you have identified may not be exactly the same as what interviewers ask. Try to phrase the question several different ways
- Find examples of how you have used your skills in the past
- Ask if you can take a support person with you if you feel more comfortable with that

Once you have the job

Other things to think about

- Organise the necessary work equipment (e.g. uniform/ lunchbox/suitable shoes)
- Identify someone in the workplace who can offer help or you can talk to about issues (e.g. human resources)

Useful supports

- Visual supports – calendars, diaries, to-do lists, flow charts
- Plan your daily route
- You may want to ask if you can record any conversations to help you (with permission)
- Noise cancelling headphones can be useful – check if this is appropriate
- You may request a quiet office space (away from others, bright lights and other noises)
- Working from home can sometimes be an option

Employment Supports

For a useful list of organisations that provide employment support, go to the Directory on the NZDSN website and select Employment Support from the Services Provided drop-down box. www.nzdsn.org.nz/directory

Autism Training for Employers

Altogether Autism provides free information for employers on autism. We also run a professional development course called *Prism* which can be tailor-made to your specific workplace. For more details go to www.altogetherautism.org.nz

Some agencies may also provide supports and services for your employer.



Photos by DOROTHY VAN DEN HOVEN

Breaking the label

TEDx speaker and mentor JASON EDGECOMBE has started a business aimed at encouraging people with autism to gain confidence and ‘be who they are’. Jason, who has been diagnosed with high functioning autism, talks to Altogether Autism’s national manager CATHERINE TREZONA about diagnosis, mentoring and Dungeons and Dragons.

*I am only one,
But still I am one.
I cannot do everything,
But still I can do something;
And because I cannot do everything,
I will not let what I cannot do stand in the way of what I can do.*

Variation of a quote by Edward Everett Hale

This was the opening quote in Jason Edgecombe’s TEDx Tauranga talk in November last year. In this talk, Jason described how he attended his uncle’s wedding in his native Canada as a six year-old. At the wedding he spent over three hours discussing marine biology with his uncle, while the adults at the table listened in silent amazement. The events of the following year stand in stark contrast to this eloquence, when Jason’s father forced a referral for a paediatric early education assessment. The diagnosis was Attention Deficit Disorder (ADD), described to both Jason’s parents and, more alarmingly, to seven-year-old Jason, as a mental disability. The specialist predicted that this diagnosis meant that Jason would have massive problems forever — most likely struggle with friendships and school, and would be unlikely to ever hold down full-time, meaningful employment. As Jason recalls, “Forever after I was the ADD kid.”

In 2013, Jason self-referred for a new assessment and found that the ADD diagnosis was incorrect. He was diagnosed with High Functioning Autism. In his words, this new diagnosis was like ‘putting on glasses for the first time — suddenly things started to make sense’. Jason, now 26, is a committed and loving husband and father. He is also most definitely meaningfully employed, as he works part-time as a transition coordinator, in addition to running his own business. It seems the Canadian school specialist’s predictions were incorrect.

Jason is the founder of Breaking the Label, a new business aimed at mentoring other people with autism to ‘be who they are’.

Jason said: “This motivation stems in part from my own experiences at school when a mentor who understood me would have made all the difference. When I struggled at school they told me I was plenty smart but I wasn’t trying hard enough. That was incredibly soul-destroying. Nothing ever felt right and nothing ever made sense. But I pushed through it. I was the weird kid and I pushed through depression and severe anxiety and self-loathing.”

In Jason’s early years, the voice of failure almost drowned out the voice of success.

His road to employment has not been easy. He has tried to set up two other businesses in the past and both failed. Jason has also experienced the worst breakdown in his life due to workplace stress as an employee in the hospitality industry.

But he refused to give up.

"It was like I had a switch in my brain that once turned on, gave me incredible determination. For example, my wife and I fight occasionally, usually over what colour we want the drapes or whether we're going to go to McDonald's for lunch. But in our entire marriage I have never sworn at her or called her anything negative. Because one day I decided I was never going to do that, and I flipped the switch and I never have, no matter how angry I've got or what state of mind I've been in, even in the middle of melt-downs."

He also learned resilience and courage playing video games. Through these games, he learned that failure can be followed by success. He acknowledges that video games cannot save your life, but they can inspire change. He shares this belief with a growing number of youth at the Dungeons and Dragons group he runs in association with Asperger's Connections in Tauranga. Dungeons and Dragons is a fantasy table-top role-playing game. Each player often has an area of speciality and their individual choices contribute to the success of the game as a whole. As Dungeon Master, Jason provides a safe, yet challenging environment for young people to take risks, experience failure and success, and to make friends.

Jason's favourite quote:

"Our deepest fear is not that we are inadequate. Our deepest fear is that we are powerful beyond measure. It is our light, not our darkness, that most frightens us. Your playing small does not serve the world. There is nothing enlightened about shrinking so that other people won't feel insecure around you. We are all meant to shine as children do. It's not just in some of us; it is in everyone. And as we let our own lights shine, we unconsciously give other people permission to do the same. As we are liberated from our own fear, our presence automatically liberates others."

From the movie *Coach Carter*

When asked what mattered most to him about autism, Jason answered that it is "the amazing things that it lets me do". And the worst thing about autism? "That every single person on the spectrum is amazing and 99% of them don't know that." This is something Jason plans to do something about. His goal is to create a nationwide network to coach others to become mentors. In this way, he hopes to help others silence that voice of failure so that the voice of success can be heard.

Jason can be contacted on email jason@jasonspkz.com

View his TEDx talk at this link

TEDx Jason Edgecombe: Do you always read the label? When diagnosis can suppress recovery.
www.youtube.com/watch?v=EFF0-a8iMs4



Dungeons and Dragons provides a safe, positive space for teens

By DOROTHY VAN DEN HOVEN

When I first met Jason to tell him about our support group, I said that the one thing parents were crying out for was a social skills group for their kids on the spectrum. Jason smiled and said, "I have just the thing". From there, we helped Jason set up the first Dungeons and Dragons group for teens as a trial.

Some of these kids don't leave their rooms and struggle socially, so it was a huge step to even come along to the group.

When the teens arrived for the first session they were very reserved and reluctant to engage but, before long, Jason had them interacting and we could hear them laughing. By the end of the first session they were all so enthusiastic and couldn't wait for the next.

These teens are on the same wave-length and Jason totally 'gets' them and is a great mentor. To the teens, it may be a fun game, but they are learning so much, including social skills, without realising it. The results have been instant and the feedback from the parents has been amazing:

"My child is a different person."

"My teen totally loves the game; it is wonderful to see them so happy."

"My teen is thrilled with the Dungeons and Dragons group and looks forward to it every week."



The trial group was such a success that the group wants to continue and we have started a second teen group, and a third group for the six to 12-year-olds.

There are several programmes for parents to understand ASD, but this group is for the kids themselves – and it is great to see happy parents too. It can be very stressful seeing your kids struggling in life and not knowing how to help them. So it is a huge relief for parents to see their kids happy and making friends. I'm sure some kids would like a life membership to Jason's Dungeons and Dragons group.

Dorothy van den Hoven is the coordinator of Asperger's Connections support group, Tauranga, aspergersconnections@hotmail.com



Dungeon Master Jason Edgecombe provides a safe yet challenging environment for teens such as Morgan Fowler, 15.

On the ladder – Dion's career journey

DION COWLEY, 23, spoke at the Altogether Autism Conference in 2015 regarding his success finding work as a person on the autism spectrum. Altogether Autism researcher TEGAN ANDREWS recently caught up with Dion to learn how things had progressed.

Dion works at Manuka Health, a company that produces honey and other related health products which are exported all over the world. He first began working at Manuka Health in March 2015 with a number of other people under the guidance of the Enrich Worx team. This allowed him to build confidence and skills while working for the company. Dion was soon recognised as a stand-out employee during a 50-hour trial period, and therefore progressed to the labelling room, a position requiring further responsibilities such as checking honey pots and making boxes. He still has regular meetings with the team at Enrich Worx to make sure he is receiving the support he needs to reach his goals.

Dion says he is still really enjoying his job, and his favourite aspect is the chance to meet new people. "My team has quite a few people in it – sometimes there's up to 10 of us working in the labelling room. When everyone's shifts change, I get to know new people."

He also loves the challenges of learning new tasks and has even set himself new goals for moving forward. "I want to get my driver's licence and keep working on my social skills. I'm also thinking about studying in the area of healthcare."

Dion believes that over the course of working at Manuka Health, he has developed as a person, becoming more confident and assertive. "I also really like being paid for my work and I'm now saving for a car."

His advice for other young people on the spectrum who are planning to find work: "Everyone is different, but keeping an open mind helps." Dion believes in being yourself and also suggests not to overthink things. He says it's better to work at a speed that you're comfortable with, do your best to make it natural, and "get into a routine which works for you".

Driving

Dion has been learning to drive since last October and thinks his current lessons and practise are going well. He had difficulty with his first instructor, who was a nice person but had a particular teaching style that did not suit Dion's learning style. He has since changed instructors and found one who has a flexible teaching style, and finds a method which supports Dion's learning to get the most out of the driving lessons.

"The new teacher has really helped my confidence. I know I can fixate on my mistakes, and get flustered and feel anxious. So I'm working on different ways to manage this while driving."

Challenges in the workplace

Dion has faced and overcome a number of challenges in the work place. To begin with, he found it difficult meeting new people, and would be quiet and reserved. As time passed, he began 'reading' people and thinking about what sort of personalities – and likes and dislikes – they have.

"Over time I was gradually able to be myself around others. Now some people even say I'm a bit of a joker!"

Dion has specific interests and he now recognises that these do not often interest his work colleagues. He tries to talk to them about topics they will find interesting, despite these being personally uninteresting to him.

"I have a real passion for history and love foreign films, but I know this isn't interesting to everyone. Now that I have learned to read people, it's much easier to get along with them."

The Enrich Worx team is part of the Employment Team which helps job seekers enter the workplace, perform job tasks, while developing a paid employment routine. This support could include goals such as, being punctual, taking lunch breaks, skill development for workplace interactions, and confidence building.

The team can help with any issues that may arise, acting as a go-between for the employee and employer. Its initial aim is to get young people ready for employment opportunities, and help match employers with the most suitable employees for the job.

Contact Enrich Worx by phone 0800 367 424 or email info@enrichplus.org.nz

You can find other supported employment agencies listed on the NZDSN directory, under Employment Support <http://www.nzdsn.org.nz/directory/>



Communicating on the job – a lived perspective

As autism affects communication, social interaction and behaviour, it can make gaining employment and fitting into various work environments challenging. TEGAN ANDREWS talks to SCOTT CAREY, a 24-year-old who was diagnosed with Asperger's at age 14, about his work, employment opportunities, how he got his job, and challenges he faced along the way.

What is your job and what do you do (tasks and duties)?

For the most part right now I'm just a retail assistant in charge of maintaining a store, cash handling and managing customer enquiries. In the past I've worked contracting for web firms designing websites, and I also freelance doing art and graphic work for my own clients wherever I'm able to find them.

How did you find your job?

The retail job was just on the Work and Income job board. I've found the web work through my old college's tutors.

Did you need any special skills or training to get this job?

The retail job, no. The web jobs have required extensive training and study.

What do you like about your work?

On some levels I enjoy the work because I find the socialisation factor challenging, so it keeps me tuned up so to speak. I enjoy web work because it has a lot of logical problem-solving involved. I've found that when I'm not doing a job that involves interacting with the community I tend to become more and more reserved.

Out of all the jobs I get hired for, I most appreciate the jobs that require creativity – the days where I'm being paid to draw is a dream come true.

Do you prefer to be a contractor and what does this mean?

Absolutely, there's joy to be had in breaking the monotony of the average work day and contracting is a great way to do that. I've worked with people all over the world and it's a great feeling having people specifically hunt you down for your skillset.

In regards to what it means, it's a lot like freelancing except you're working with the same company and people each time. These people will handle other issues of the business that you would normally have to deal with yourself in freelancing such as accounting, marketing, networking and interacting with the client.



What challenges have you faced in your job?

I have struggled a lot with communication obviously; it's why I prefer contracting to freelancing, because it just makes things so much easier when it's someone else's job to interact with clients and figure out what they actually want and what the issues with their vision are.

Retail takes a hit too. I never quite know how to handle a lot of the social situations thrown at me and I often respond with very formulated responses. Interpreting speech takes a lot of effort for me and sometimes when important details are relayed to me it can be difficult to take it all in due to intense social anxiety; this can easily cause problems down the line, when it starts to seem like I'm ignoring orders or guidelines.

I've been told that I put on accents when I'm socially nervous which is very embarrassing. Whether this could be chalked up to Asperger's, social anxiety or just me as a person is a mystery to me. So far I've gotten American, Canadian, English and even Scottish!

I have always struggled with the 40-hour work week and I think I always will – it is very rare that I will spend that much time working. This is not because I am lazy, I could easily do 40 hours a week of work at home contracting, but whenever I've done jobs such as retail, I feel like my Asperger's definitely does start to get in the way. I start to show tell-tale signs of stress, such as having involuntary jittery wrist, head and eyelid movements; I also begin to zone out a lot more and start to feel emotions very akin to how one would describe depression.



Illustrations by SCOTT CAREY

How have you overcome some of these challenges?

Some have been overcome and some have not. Before I mentioned that it can be hard for me to gauge what people actually want from me, so when I'm contracting or freelancing I started writing down everything the person said and then relayed it back to them, rewording it to make sure we're on the same page. It sounds pedantic, but I find that my thought process differs from other peoples' quite significantly. If I feel the person I'm speaking with would be comfortable with it, I'll also record conversations on my phone to think back on later. I find myself faking personalities, depending on who I'm with, to try and seem less disinterested – which could explain the aforementioned spontaneous accents, however, it's hard to gauge whether or not this is just normal human behaviour.

How did you find studying to be a web developer and graphic designer?

I loved it! Some of my fondest memories are from my time spent at Vision College. My time spent studying felt a whole lot more natural; other people there seemed a little different as well, so maybe that helped. I'd chalk up my ability to code proficiently and my creative thinking to Asperger's.

Do you have any advice for other young people on the autism spectrum entering the workforce?

Be true to yourself. I think I tried to be someone I wasn't for way too long, I subdued myself or faked quite a lot. As with most personality traits, I find if you take pride in them and rock them, they can come across in a positive quirky light. It's very true that

I've alienated a lot of people with the things I say and the way I act, but in doing that I've also made good friends and entertained a lot of customers and clients.

Anything else you would like to add?

I want to mention the struggle of not really knowing where to draw the line between Asperger's and who I am as a person. All my life I've been told I've had Asperger's, but it can be very hard to gauge what actually is a result of this neurodevelopmental condition and what is just me as a person gained through my experiences. These sorts of thoughts can lead me to wonder whether or not I enjoy having the syndrome or not. I think about how I might change if I did not have the syndrome and I'm still not really sure what I'd be like.

Up until I was around 21 perhaps, I didn't even really acknowledge that I had it, nor did I tell people that I had it (especially employers!). Now that I'm a bit more mature and I've had a bit more insight into the differences that people experience growing up, I can start to see oddities in my time growing up. Throughout my teen years I never really left the house or lived life. I was content to just sit in my room and do tedious hobbies such as gaming and drawing. I don't mean to sound pessimistic about those – I love them very much – but I do wish I could have had a more standardised teenage life.

Other oddities that stick out to me are situations like trying to get out of major life events such as my sister's wedding or not mourning the loss of my mother, who was a really terrific person to me. Being so detached, fake and flat, it became very easy to dismiss myself as a sociopath. I've had very little faith and trust in myself at times. To tie this back to employment, I feel like these traits and fears have held me back tremendously. I'm not quite sure how I've managed to land jobs in retail and sales.

View Scott's work at www.rivetcreative.co.nz

The disclosure dilemma

For those of us fortunate enough to be gainfully employed, it's a sad reality of workplace life that we'll often struggle to 'fit in' in one way or another

Because autism is predominately a sensory, social and communication impairment, it is natural to expect that this will manifest itself when working alongside others, such as those colleagues who might be loud, smelly, or like to shake hands and have no idea the turmoil their actions might cause us. They're just trying to be friendly, and are behaving according to some vague unwritten social code.

For many of us on the spectrum, the missed cues, inane lunchroom conversations, the vague directions that we might be given, just don't make sense. It's like learning another language – the language of the workplace. And like any foreign language, some of us will pick it up more quickly than others. Some will come to terms with the language of the workplace, some never will. How this will be tolerated by our colleagues will depend on our workplace and how well our other abilities make up for our challenges.

Despite these challenges, many of the adults with autism that I know, myself included, are employed. Many are successful in both their work and private lives, with spouses, children, houses, cars, and the other usual things that typify a happy life. What further typifies us is that while we may have had challenges in learning to navigate workplace language to an extent, our neurotype gives us strengths that are well-suited to the job. One of us is a successful psychologist and a published author. Another is a teacher, where the ability to work alongside and empathise with those with disabilities is a huge advantage.

For myself, my encyclopaedic knowledge of my workplace – having a visual map of hundreds of valves, tanks, electrical devices, and the like, and how they are interconnected – is a huge advantage to my employer. It's because of these things that our quirks are tolerated, because we're good at what we do. So what if we aren't a social butterfly in the office, right?

Except it's not always that easy. We're not just judged on our ability. The language of the workplace dictates that we must 'network' at staff functions. We must make inane small talk, whether we care about what people did in their weekends or not. At the lunchroom table, we're expected to sit next to the colleague with the tuna sandwiches and not retch.

Because of the way our brains might work, we're planning the conversation or activity far ahead, to try and have some vestige of self-control. All of this comes at an emotional cost. I used to get home from work and hide in my bedroom for an hour before



I could face my family; now I stop off on the way home. And no matter how hard we try, we're going to be the quirky one anyway.

One obvious solution, from the outside looking in, is to disclose. At least then our workmates might understand, right? Maybe. Workplace disclosure is a minefield, and once you've disclosed you can't take it back. Some of us want to disclose but, when we approach our manager, are told not to. Some of us are concerned about being stigmatised or judged, so we can't bring ourselves to disclose.

My experience with being semi-disclosed at work has had both positives and negatives. Only my immediate manager and HR know I have autism; my colleagues don't, as far as I am aware.

The oxymoron here is that a great way to encourage acceptance of autism in the workplace is to show that people with autism are already employed and good at what they do, but unless we share our 'secret', this will be slow to happen. People's understanding of the spectrum will still be limited to their neighbour's cousin's son who has autism. They will have no idea that the person they are working alongside, with their quirks and lack of filters, sits on the spectrum also. It could be that the only way we can begin to understand the language of the workplace is to take the first step ourselves.

By a person on the autism spectrum who wishes to remain anonymous

Some kind of strange not-quite-Aspie, not-quite-NT hybrid

RACHAEL WILTSHIRE is currently studying part-time towards a BA/ BSc in History and Earth Sciences. She was diagnosed with Asperger's syndrome in 2006 when she was 12, and has since had a strong interest in the autism spectrum. This year, she has established a blog and Facebook group for girls and young women on the autism spectrum. In her spare time, she enjoys dancing and drama.



Ten years ago, partway through a horrendous year during which I failed spectacularly to cope with the transition from primary to secondary school, I was diagnosed with Asperger's syndrome. My initial reaction was one of relief; after years of secretly reading mum's parenting books, I assume in an attempt to figure out why I was different, I finally had a search term I could use to find books about me.

The only problem was that even these Aspie books didn't quite describe me. Remember, this was 2006 — there weren't that many books about girls on the spectrum back then. And so I questioned whether I was really an Aspie, or whether I was some kind of strange not-quite-Aspie, not-quite-NT¹ hybrid.

Of course, there are now many more books available for girls on the spectrum; my favourite is Jennifer Cook O'Toole's *Sisterhood of the Spectrum*. Nevertheless, in New Zealand at least, there is still a lack of spaces where girls and women on the spectrum can meet each other.

Ever since I was diagnosed, I have wanted to meet other girls on the spectrum. Despite people's warnings that 'other Aspie's won't be exactly like you', I assumed it would be easier to get along with other Aspies because if you did or said something a little gauche it wouldn't matter. When I did finally meet some other Aspies, I found that that was indeed the case. But whilst I have been lucky enough to serendipitously bump into other Aspies, it was sheer luck that we met each other and discovered that we were both on the spectrum. After all, I don't have a label on my forehead stating that I am an Aspie.

So, for a long time I have wanted to create a group where girls on the spectrum can meet each other. This year, I have finally achieved that goal. I created a blog (<http://butterfliesandrainsbowsaspieblog.weebly.com/>) where I post about my experiences as a female on the spectrum. The blog is linked to a Facebook group (<https://www.facebook.com/groups/451216675075954/>) where girls and women on the spectrum can chat to each other.

So far, the group seems to have been very successful and it has been wonderful seeing how many experiences we share. For me, it has confirmed that I'm not some kind of strange not-quite-Aspie, not-quite-NT hybrid; I'm just a typical female Aspie. The members of the Facebook group are a wide range of different ages, and this has proved useful as it means that the older members of the group can give support and advice to those younger than themselves.

If you would like to get involved with this community, we would love to have you. Please feel free to join the Facebook group, comment on the blog posts, message me through the blog site and share the link with anyone you think might be interested. I hope that we can build up a thriving community of girls and women on the spectrum, so that those who want to meet others like them will have somewhere to turn.

¹ Neurotypical is a term widely used by the autism community to describe those who are not on the autism spectrum

Circles of Support encourage positive transition



By JENNY GIBBS,
Consultant Psychologist

The transition from the relative safety of the school and family environment to the world of independent living can be scary to contemplate for young people with autism and their families, so creating a Circle of Support is an option that can help with this process.

A Circle of Support is a group of people who are intentionally invited to come together in friendship and support of a person with a disability, for the purposes of protecting their interests into the future.

We know there is a limited amount of government-funded support and the reality is there will never be enough for all those who may have needs. Creating a Circle of Support is one way in which families, their extended family, friends and wider community can assist meaningfully in supporting a young person with autism.

It's about making a positive change, sharing ideas with allies, having people who care and are willing to watch over a vulnerable family member.

"A Circle of Support can be called anything, for example champions, coffee circle, social circle or intentional network. What is important is that there is a purpose for bringing people together who are unpaid, who care about and have the best interests of the disabled person at the core" (*Te Pou newsletter*, August 2012).

There are numbers of services and initiatives out there who can provide information on Circles of Support and other ways of assisting people with disabilities achieve their short and long-term goals.

These include Lifestyle Interactionz, www.lifestyletrust.org.nz; Imagine Better www.imaginebetter.co.nz and Enabling Good Lives www.enablinggoodlives.co.nz

NETWORK MEETINGS

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Learn about all that Altogether Autism can do to support you. Be upskilled on autism from both a professional and a lived experience viewpoint. Have your questions about autism answered. Enjoy light refreshments with others living and working with autism.

UPCOMING MEETINGS:

GREYMOUTH • WEDNESDAY 22 JUNE • 7PM - 9PM

Kingsgate Hotel • 32 Mawhera Quay • Greymouth

UPPER HUTT • THURSDAY 23 JUNE • 10AM - 2PM

Upper Hutt Cosmopolitan Club • 11 Logan Street • Upper Hutt

PORIRUA • FRIDAY 24 JUNE • 10AM - 2PM

Porirua Community Centre • Level 4 • Pember House • 16 Hagley Street • Porirua

HAMILTON • THURSDAY 11 AUGUST • 10AM - 2PM

Venue to be advised

TAUPO • THURSDAY 1 SEPTEMBER • 10AM - 2PM

Taupo Library • Hone Tuwhare Room • Taupo

PLEASE INVITE ANYONE WHO IS INTERESTED

RSVP: WWW.ALTOGETHERAUTISM.ORG.NZ OR 0800 273 463

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