

AUSCA AUGE AND EXPERIENCE

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, autistics and family members of people with autism.

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



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Cover: Turaukawa Bartlett with his son Varden. Design: Tamara Miles

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Fathers on path to autism acceptance



WE ARE DELIGHTED to bring you the special stories of "Dads and Autism" included in this edition. We know from previous readership surveys that we have more women than men reading our Journals, so we are especially grateful to the fathers and families who shared their journeys. We hope these powerful stories of fathers and their autistic sons and daughters will inspire and encourage you.

In addition to the stories, we have looked at the research into fathers and autism and found that fathers are often overlooked by researchers. A study in 2017 aimed to address the under representation of the experience of fathers in autism research. Burrell, Ives and Unwin (2017) conducted semi-structured interviews with eight fathers to help service providers have a better understanding of the fathers' perspectives. They described their experiences as a journey through frustration with acceptance being their turning point. A key conclusion of this study was for service providers to ensure fathers feel able to communicate their frustrations to health and service providers and be supported in their journey to acceptance.

A 2019 systematic review of the impact of fathers' involvement on youth, families and intervention concluded that current research suggests that fathers of autistic offspring were less likely to be involved in parenting compared with mothers and compared with fathers of children with other disabilities. This review found that fathers were able to effectively implement a range of interventions, and the reviewers considered that this could provide unique benefits to children on the autism spectrum (Rankin, Paisley, Tomeny, & Eldred, 2019). If you would like a copy of either of these articles, please contact us via our website or email info@altogetherautism.org.nz

By autistics, for autistics

Thank you to those who caught up with us at our Connecting with Community network meetings around the country. We have been trialling a new format for network meetings, with a "By Autistics, For Autistics" meeting taking place at the same time and place as a separate meeting for families, whānau and professionals.

We will be offering this dual programme format at various locations around New Zealand in the coming year. Keep an eye out on the Events tab of our website or on our Facebook page.

We also have an additional workshop to offer as we continue to travel around New Zealand, with our brand new "Kids do well if they can" workshop. This draws from the work of Dr Ross Greene, American child psychologist, and pushes back against the idea that "children won't" with the idea that "they can't". In this workshop we teach skills to reframe the way we see 'challenging' behaviour, so that we become detectives, looking to remove barriers to our children's success. We will be offering this free workshop in a range of locations around New Zealand, including Gisborne, Central Lakes, Taranaki and Hawke's Bay.

We are excited to be bringing our PRISM professionals development workshop to new places in the coming months. We were in Hokitika and Christchurch in August and will be in Kaitaia in November. These workshops are for all professionals working with people of all ages on the spectrum.

If you would like to be added to our database to make sure we keep you up-to-date with all these events, get in touch with us via Live Chat, our website, phone 0800 273 463, or email us at info@altogetherautism.org.nz

I hope to see you at one of these events soon. Me te mihi nui / In appreciation.

Catherine Trezona National Manager, Altogether Autism

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Getting the right learning supports in place



Associate Education minister **Tracey Martin** launched the new Learning Support Action Plan 2019-2025 in July at Green Bay High School in Auckland. She writes about her delight with the plan and the subsequent announcement about where the learning support coordinators will be located.

THE NEW Learning Support Action Plan, where the first tranche of learning support coordinators will be located and the \$600 million extra this Government has put into learning support, shows we are finally rebuilding our education system so that it is fair and meets the needs of all students.

This includes the one in five who have learning support needs – and that important group of children with mild or moderate needs who really haven't been well served by the previous system or funding of learning support.

There is also some personal satisfaction in that this need has been known by parents and schools for a long time – which was why in Opposition I worked with Chris Hipkins and Catherine Delahunty to get a Select Committee Inquiry in 2015 into identification and support for children and young people with dyslexia, dyspraxia and autism spectrum disorders.

Four years on, as Associate Minister of Education, I've been able to do something about the issues that were made public.

The Action Plan responds not only to the select committee findings but to extensive feedback from a wide range of sources, including children and young people and their parents and whānau, schools and early learning services and other professionals.

It focuses on six strategic priorities that we think will make the greatest difference to children and their learning over the next few years:

- introducing the first tranche of learning support coordinators in schools and kura kaupapa
- developing new screening tools to help the early identification of learning support needs
- strengthening early intervention for pre-schoolers
- creating a flexible set of services and supports for neurodiverse children and young people
- better meeting the learning needs of gifted children and young people
- improving education for children and young people at risk of disengaging.

The first tranche of 623 learning support coordinators have since been allocated to 124 clusters covering 1052 schools and kura, and they will start work from January 2020. This new, fully funded role is solely focussed on learning support, and my intention is to roll it out more widely in future years.



CELEBRATING: Altogether Autism has been delivering Strengthening Early Learning Opportunities (SELO) programmes, funded by the Ministry of Education. Our facilitators Cat Noakes-Duncan and Martyn Matthews spent two weeks in Queestown/Lakes/Central Otago in June and July working with a range of committed and enthusiastic early childhood teachers.

The aim of the programme is to enhance teachers' strategies as they work with children on the autism spectrum, with Attention Deficit Hyperactivity Disorder (ADHD) or with emotional and behavioural difficulties. Twenty one early childhood teachers, education specialists, parents/whānau and Ministry of Education staff attended the foundation workshop in Cromwell on June 5. Our specialist facilitators then followed up with centre visits to 11 early childhood centres through the region. The programme ended with a celebration workshop on July 26.

Pictured celebrating (in no particular order) Nicola Brown, Sharon McCulloch, Pip Pedofsky, Anne-Leah Shaw, Michelle Calitz, Desma Dsouza, Tegan Coote, Jess Harvey, Brigetta Smith, Jade Hinton-Dewey, Brad Collier, Nicola Roberts, Ernie Mather, Chris Cooper with facilitators Cat Noakes-Duncan and Martyn Matthews.

I would encourage parents and educators of children and young people with autism to read the Action Plan. The plan will continue to be reviewed and revised as needed. It is part of a broad programme of education changes that will improve learning support.

Finally, I would also encourage you to make use of available programmes and support such as Incredible Years Autism programmes, which provide early, targeted support for children aged 0-8 years and for their parents and whānau as well as teachers.

There is strong evidence to suggest that early intervention has the greatest potential to improve future outcomes for children on the autism spectrum. The programmes are about helping these children develop positive social interactions and communication skills.

Tracey Martin was first elected to Parliament as a New Zealand First list MP based in Warkworth, in 2011. Her portfolios are as Minister for Children, Internal Affairs and Seniors and as Associate Minister of Education.



MANAVATION: Turaukawa, Aimee and Varden Bartlett at home in Karangahake Gorge.

He taonga te takiwātanga – autism is a gift



Being Māori and a father of a child with autism are precious gifts, **Turaukawa Bartlett** writes, left to us by our ancestors.



Imagine having a best friend Imagine spending all your day with them, going places, laughing together, eating together Imagine that every time you see them, they call out for you, give you the biggest smile and raise their hands for a hug

Imagine loving that best friend more than anything else in the world

Imagine thinking that you were going to spend the rest of your life with this person, making sure they were happy and lived the best life they could ever live Imagine having that connection.

Now imagine one day your best friend is different Imagine they no longer want to spend the day with you, they don't want to go places, laugh and eat together Imagine they don't notice you anymore, they don't smile at you anymore, they don't raise their hands for a hug, call out for you, and they don't even look you in the eye anymore

Imagine you are no longer friends Imagine you are simply a father to child living in a world where you don't exist Imagine feeling that disconnection This was our story.

AS A CHILD of whāngai/adoption, I was raised by my grandmother in Ōrākei, close to my marae. This was an environment of manaakitanga; everything we did as a whānau was underpinned with the aim of enhancing each other's mana. It was an environment where I knew who I was, where I belonged, and above all where I felt connected.

Every morning before school, my grandmother would take me around the bays where she would teach me about my ancestors, my people and the whenua/land. I would then practice saying my whakapapa/ancestry, and whilst I didn't realise it at the time – I fell in love with the journey of mātauranga/seeking knowledge and excelling in everything I did. My grandmother also taught me the mana of hard work and would set me weekly tasks to achieve, like memorising my timetables. I was a very task-orientated person and enjoyed the concept of working towards a goal – doing something for a reward. I flourished in the routine-filled environment and the security of knowing the what, when, where, who and why something was happening – I always felt in control. I felt safe.

The shift

At age nine, my grandmother was starting to get older, and I was getting cheekier. It was decided that I would return to live with my biological mother, stepfather and brother. However, this was a complete contrast to the world that I was used to, and belonged to.

There was no te reo spoken, we didn't practice tikanga, and being Māori wasn't the thing to be. This was the first time I felt alone, without an identity and without a connection. It was then that the little voice in my head started to say, "you were given up as a baby, and you've been given up again, no one wants you".

After a couple of years of hearing this message, and fuelled by a disintegrating relationship with my new family, I started to rebel and begun to get involved in a street gang. We started drinking, taking drugs, stealing, fighting other gangs and at 14, I had been expelled by two colleges and had no job options. However, whilst this was all happening, there was one thing that I was receiving; a sense of connection, purpose and belonging. Inside the gang, we looked out for each other, we learnt from each other, there were protocols that gave the group structure and a sense of security and safety – this was what I yearned for.

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At age 20, and having spent six years with my partner Aimee, we had both become involved in a world where alcohol and drug use, gangs and partying had become the norm; we were both out of control and heading towards a dead end.

Varden Turaukawa Bartlett

In 2010, Aimee fell pregnant, and even though I didn't know it at the time, this was the beginning of the change. When Varden was born, I realised that he was the true sense of connection I had been yearning for since I was that nine-year-old little boy.

In a search for a new beginning, Aimee and I soon made the move to Perth where Aimee had whānau. I had trained as a butcher, and I found a job in a smallgoods store. There was a

strict routine and structure that I loved, and before I knew it, I was offered a rentfree home and a pathway into the business.

Aimee was able to stay at home to look after Varden, and at 18 months, he could say mummy and daddy, he was a smiling, happy and a 'normal' little boy – life was perfect!

He Māori ahau, he tangata whai takiwātanga ahau, he kaitiaki au mō taku tamati, he taonga ia, he taonga te takiwātanga i waiho ai e ngā tūpuna ki a tātou. Mauri Ora!

I am Māori, I have autism, I am a father of a child with autism, and they are precious gifts left to us by our ancestors.

could stand proud and call home. We built connections with the amazing whānau from Goldfields school, and after a year at home, Aimee had begun her journey into becoming a counsellor.

I had just started a role as a whānau support worker also as we both realised that our experiences were actually strengths that we could use to support others in our community – Varden's future community. I reconnected with my reo and te ao Māori; and the feeling of whānaungatanga that I once knew had returned.

Four years later, we find ourselves in our own home, on our own piece of whenua, entrenched in our culture, running our own wellbeing business and above all, Varden has a sense of connection. Varden is now a smiling, boisterous, affectionate

and kind nine-year-old boy. He loves school, loves singing waiata, dancing and has achieved three things we never thought were possible. Going to the toilet, making himself a kai, and can say I love you – "I yuh yuu!".

Over this time, I've also received a diagnosis of Asperger's, and it has been one of the most powerful

experiences that we have ever gone through as a whānau. It made a lot of things about my childhood make sense and it also gave us a deeper insight into the world that Varden lives in.

Now when I look at Varden, I realise that even though Varden isn't a big talker, he speaks through his eyes and heart. Even though Varden isn't a crowd person, he can make you feel like you're the only person in the room. Even though Varden isn't a big reader, he can read our wairua and know when we're not right. And finally, regardless of the fact that Varden isn't an academic by 'normal standards', he is a master in the art of manaakitanga; one smile can remind you of how important you really are to him.

The change

I can remember it like it was yesterday. It was a normal day, and just like any other I opened the door and went up to Varden expecting the normal smiling response. However, this time something was different. There was no smile, no hug, no sounds, no eye contact, nothing. It was as if someone had taken my boy and left an empty shell – we knew something wasn't right.

Shortly after, we started noticing a few different things like the tippy toes, the flapping, the stimming noises and an overall sense of disconnection.

As time went on, Aimee and I reacted differently. Like many parents, Aimee started consulting 'Dr Google' and researching everything she could to find answers, whilst I chose the easier route – denial. I didn't want to accept that my little boy was different or that there was something wrong.

At 30 months old, Varden was diagnosed with severe autism. The little voice in my head returned, but this time the message was "this is your fault, you're a failure as a dad, not even your son wants you".

To help deal with the voices, I turned to what I knew would help – alcohol. For the next year, I started drinking heavily again, and as Varden's symptoms worsened; the meltdowns and late-night screaming matches, so did the fracturing of my relationship with Aimee. It got to the point where I started asking those age-old questions like "why us?", "what did we do wrong?". I soon arrived at rock bottom, and got to a point where taking my own life had become an option; a way out.

It was then that the thought of Varden growing up without a whānau, a father and a sense of connection hit me like a ton of bricks and forced me to ask the question – "What would have happened if my grandmother had turned her back on me?". Picturing her face, I made the decision to bring my whānau home to what I knew gave me a sense of wellbeing in my early years – whānaungatanga.

In 2015, we arrived in Paeroa and changed our whole life to surround Varden with whānaungatanga; connection to his culture, his people and his turangawaewae – a place he

What we want to tell other whānau

Don't give up! Takiwātanga is exactly that, people finding their own time and space. As a Māori whānau, we've realised that Varden's journey is a taonga, a precious gift that that has taken us on our own pathway of whānau development and re-connection. When we look into Varden's eyes, we don't see autism, we see our boy, we see our taonga, we see our reason for still being here to tell the story, and above all we see him feeling a sense of whānaungatanga in his own time and place.

So imagine now that your best friend starts to recognise you again

Imagine they start smiling at you, and even give you the odd hug here and there

Imagine your best friend is now your little boy again Imagine knowing that you'll never be apart again Imagine realising your grandmother saw something special in you, and knew one day you would use her teachings for a special purpose

Imagine realising that purpose was Varden...

Imagine that connection.

- Turaukawa Bartlett is a specialist in hope and inspiration.
 He is a director of Manavation and a social influencer.
- Takiwātanga is a derivation of Keri Opai's phrase for autism: "tōku/tōna anō takiwā" – "my/his/her own time and space".

My little buddy creates parenting challenges



Every day is so different for proud father **Gareth Rogerson** as his autistic daughter Paige makes him laugh, cry and shake his head in disbelief and frustration. He loves her to bits and is learning how to parent differently.

EACH MORNING, when Paige wakes up, it is like a box of chocolates – you never know how much Autism Spectrum Disorder fog you are going to encounter.

Imagine a pizza that has eight slices. Each of those slices represent who she is, i.e. one piece is fixed mindset, one-piece communication, one-piece anxiety, another concentration etc.

When she wakes you are hoping for the best, that all eight are functioning but some days, only one or two pieces are connected and not fogged in. These days are hard, both for her and the rest of the family.

Paige, six, is our youngest daughter and an IVF miracle like her older sister Phoebe, eight.

When Paige was born here in Tauranga there were no signs of anything untoward and she developed as a neurotypical child was expected to. She did get numerous ear infections and suffered with croup from a very young age and at two had grommets inserted and adenoids removed.

This helped for a while, but we were constantly at the doctors. Paige started to make noises as expected and began to try and say words at the same developmental stage as her older sister. She was different though. When she spoke, she knew what she was saying but no one else did, she struggled to get her tongue in the right place.

At the age of three we took her to private speech lessons. Phoebe could understand her and would interpret her words, we could understand some words but none of our friends and family could. Paige relied on Phoebe to speak for her. Speech progress was very slow and at times extremely frustrating and her engagement was limited.

My wife Jolene became concerned with her interactions with other children. Paige was cared for in our home by a nanny as we both worked full time. She attended play groups each day but would isolate herself. She would play on her own. If all the children were painting, Paige would be in the sandpit. If all the children were in the sandpit, Paige would be painting. She was happy to do things on her own and sometimes did not know how to play with the other children.

At four, we enrolled her into a childcare centre to try and encourage socialisation skills. She did make a friend and they were stuck together like glue. At this point we noticed that she tended to follow what the other children were doing, if they sat on the mat she would follow, if they washed their hands for lunch, she would do the same. Little traits started to happen that we had not seen in our older daughter. If we went somewhere new, she would cling to us and hide her head, she would rely on Phoebe for security. She began to get fixated on things, if she had an idea in her head of how something had to be then she could not cope if it didn't



FATHER-DAUGHTER: Gareth Rogerson with his daughter Paige.

turn out that way, if she started something then she had to finish it before she could move to the next task. If things did not go to plan or as expected, then she would have huge meltdowns. The older she got the more violent these became.

We tried every technique you could imagine, timeout – she screamed louder, taking her favourite toy off her – she would tell us she never really liked it anyway, going to bed early – she would just keep getting up till her sister went to bed. Reward chart after reward chart but everything was short lived with Paige.

Jolene and I were really struggling and would play tag team, tag you're in so that the other person could get a break hiding in the bathroom for 10 minutes. Every night was a fight with her, just getting her to shower would turn into a screaming match and it would take up to 2 ½ hours some nights to get her to sleep.

Paige slept with my wife on many occasions as we had to give in when the time was nearing midnight. It was having a huge toll on the both of us, we were so sleep deprived that our patience would be constantly running thin, a vicious circle.

It was also really affecting Phoebe.

Because so much time was being spent trying to cope with Paige, she was being forgotten. Phoebe would try and act up on occasions just so she got our attention even though it was negative attention. The hardest thing was seeing how mean Paige could be towards Phoebe.

One minute they would be happily playing a game, it would be going great, everyone was happy – next minute – Phoebe would be crying as Paige had physically hurt her. This violence continued to get worse but was only ever directed at Phoebe or my wife, Paige did not understand what her actions felt like.

Jolene didn't know what else to do and took her to our doctor. He gave her melatonin to help get her to sleep at night. It did work a little which meant we all got a little more sleep but if she was having a meltdown then there was no way you could get her to sleep. Paige's meltdowns averaged 2 ½ hours of constant screaming, throwing anything she could, stomping and kicking walls.

Not knowing what else to do Jolene turned to the internet and asked Dr Google. After hours of research came up with the idea of Oppositional Defiance Disorder (ODD). We were convinced this was her as everything seemed to fit. We found a psychologist that specialised in children and took Paige there each week to try and find strategies to help.

We took Paige for about six months and each week we did discover more and more unique habits and traits; but the psychologist still could not pinpoint anything specific. She had the feeling that Paige had Attention Deficit Hyperactivity Disorder (ADHD) as she couldn't sit still for any length of time or focus on what needed to be done, which was contributing to the other problems we were facing.

All this time my wife was begging for help through the public system, but she just kept being brushed off as we didn't qualify or fit the mould.

We are now on the wait list to see the paediatric team.

After a very emotional chat with the psychologist, she referred me to a psychiatrist that specialises in children and one that would be able to meet Paige and diagnose her. We met him privately in our home and he spent some time with Paige. He was clear that Paige had ADHD.

It was not what I was expecting, we then talked through the options and what that meant for Paige and our family. We decided to put her on a trial course of medication to see if this would help.

Paige got worse, if that was possible. Her meltdowns were more frequent, she became more aggressive hitting and pinching my wife, kicking out at us and more fixated. After a week we again met with the psychiatrist and we explained that he got the diagnosis wrong, she was worse. He just smiled and said "I thought this would happen" I didn't quite know what he meant and didn't feel very confident. He then went on to say that by medicating her ADHD it has now highlighted her other symptoms and he could then confirm a diagnosis of Autism.

I was not prepared for this at all. Autism, what is autism and what am I meant to do with that?

Jolene and I had a long chat with him, he explained how it was very common to be diagnosed with both Oppositional Defiant Disorder and autism at the same time.

Talking over the options we

decided due to the severity of her meltdowns, fixed mindset and aggression we would try medication. Paige has been on medication for about five months and it has taken a while to get it right and to really see the affect it has on her.

We still get the meltdowns, but they are over quickly, she can still lash out but can now recognise the impact and apologise after and she is beginning to learn calming and coping strategies.

Getting the diagnosis was a relief. We were assured that it wasn't us, we weren't failing as parents and it also wasn't her. We just had to learn and understand who she was and how she saw the world.

We have now attended several courses and have spoken to other people in a similar situation. I have learnt that it is me that must change and not Paige.

Paige is Paige, she sees the world differently to me and it is my job as her father to learn how to support and parent her the way she needs it.



FAMILY FUN: Gareth and Jolene Rogerson with daughters Paige and Phoebe.

I was told that you cannot parent an autistic child in the same way as you parent a neurotypical child and every autistic child is different.

I had to and continue to try and understand her.

My wife and I now approach parenting differently.

We learned that we needed to slow down, look and listen. When we did that why she did things and reacted the way she did made

sense. There had always been a reason behind them, it was just different to ours and what was neurotypically expected.

We keep a strict routine during the week with clear expectations. Paige knows exactly what to expect and what is expected of her. We haven't mastered it yet and there still is lots to learn.

I wouldn't change Paige for the world, her loving nature, willingness to help and her extremely quirky personality makes all the hard work worth it.

We still have a long road ahead and we will meet lots of obstacles along the way but each day we learn more ways to help Paige embrace who she is. As she gets older and her understanding matures, I am hoping she will be able to self-manage and recognise triggers.

All going to plan, I would have taught her the skills she needs to overcome these and be the amazing person she can be.

Gareth Rogerson is a Tauranga-based electrical fitter.

"We learned that we needed to slow

down, look and listen. When we did

that why she did things and reacted

the way she did made sense."



Ten kids, full of life



A large Te Aroha blended family have multiple children in the household – and a dad – on the autism spectrum. They spoke to **Monica Holt**.

They can do whatever they want. I don't believe that disability is a stumbling block. We just encourage them all the time that they can be who they want to be.

MOST DAYS, 10 children come in the door at the end of the day.

"Routine, definitely we have to have routine,' says Rebecca, mum to her own five children and step-mum to her partner Daniel Smith's five children.

Rebecca and Daniel live with their 10 children in a large busy household in Te Aroha in the Waikato.

Rebecca's two youngest, aged 9 and 7, are on the autism spectrum and all five of Daniel's children, aged 6, 8, 10, 14 and 15, are too.

It presents some unique challenges for the blended family who have hugely varying needs.

Daniel's only daughter is 8. She has been non-verbal for most of her life and has high needs when it comes to certain life skills like toileting. One of his sons has Attention Deficit Hyperactivity Disorder (ADHD) and is on medication while at school.

Some of the children are highly intelligent.

When Rebecca, 40, talks through the household's typical after school routine, it gives some insight into the way they live day-to-day and the challenges they face, when all 10 children are with them (time is split with the other parents on both sides, for part of the time).

The routine, from the moment they walk in the door, is strict.

"In our house, they get home and first they have to get out of their uniforms," says Rebecca a full-time stay-home mum.

"We sit them down, they have the option of eating what is left in their lunchboxes as they are not big eaters.

Our children find it difficult to eat at school as they do not like being around lots and lots of people."

As with many children on the autism spectrum, technology is a huge part of their lives.

If they don't have homework the children are allowed an hour each on the electronic devices in the home, which includes two Xbox Ones, a PlayStation 4, a Switch, three laptops, an iPad and Chromebooks for the older four who are at college.

If there is homework, it can be full-on. "I am usually sitting around in the lounge with five different children doing five different things. It can be really fun, as with the primary aged kids we can make it into a little game or competition. They are all trying to learn and all trying to get it right."

Next is dinner preparation, a huge catering-scale exercise. "I usually get one or two of them to help with things like peeling potatoes or unpacking the dishwater or generally cooking as we are trying to teach them all to have basic cooking skills."

It is about this time, that Daniel, 41, walks through the door having driven home from his full-time job as a technical specialist in Immunohistochemistry at Waikato Hospital in Hamilton. He is responsible for the team which does specialist testing, following patient biopsy or tissue removal, to assist doctors in making a diagnosis.

His day starts with a 5am wake up, and he is on the road by 6am to be at work by 7am.

He is home in time for dinner and to help with the bed-time routine.

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The children go to bed in different groups depending on their ages.

"The little ones go to bed at half past 7, the next age up at 8, and our big ones go to bed at 9.30pm," says Rebecca.

"In the evening they all get their time on their own with either Dan or I and we play board games or cards or do things with a group of kids, so they all get their individual time."

Daniel himself is on the autism spectrum. He was diagnosed as a child the UK, but he was not told. He learned when he was aged 34.

This, he says, caused some resentment towards his mother, and contributed to the breakdown of his marriage. But now he takes a pragmatic view about the family's challenges, including his own.

The long daily commute to his job is his thinking time.

"I have mechanisms that I can cope with it and that has taken many years of practice. I do a lot of processing when I drive."

On top of his busy home and professional life, he is also a member of Altogether Autism's Consumer Reference Group, which is a way he can share his knowledge and help others.

Like the children, Daniel also has a love of technology.

"Gaming is another entity where I can switch off from the outside world and enjoy my own world. Fortunately, it means I can also tie into their world too, if that is what they want to do. It is advantageous for me if I want to unwind from the day, I can turn a game on and usually one or two of them will either watch or join in and come and talk to me about the day, in between playing the game or telling me what to do."

This time out is important.

"Life can be extremely busy, and being on the spectrum myself, can mean I forget to take care of myself as I am taking care of everyone else."

They live on a large section so there is plenty of space for the children to play outside in the summer months.

"Te Aroha has got the wetlands just over the road from us, and the primary school has got a good playground so we will

take the bat and ball down there or do a bit of badminton or kick around with a football," says Daniel.

The children attend mainstream schools.

The children do spend time with their other parents, so it means occasionally Daniel and Rebecca have time to themselves.

"Dan and I don't get a lot of time together as you can imagine with having 10 children. But when they are at their other parent's places, we take advantage of that and we go to the cinema or something like that to have some time out to recharge."

Rebecca says good communication is the key to making things work. "It is really important in the family. So, if any of the children have any problems at all we have taught them all to come and communicate. And with kids with autism that is not just talking, so we have other ways to communicate."

The family is aware of other's misconceptions. "I get very annoyed by people who have come to me and said, 'they do not look autistic.' We have some very, very, intelligent kids, but we have some with difficulties as well," says Rebecca.

"We have children who cannot toilet properly still. We have children who can't sleep properly and who have behavioural issues."

She knows when to ask for help, or to accept help when offered it.

"I get told all the time I am 'super mum' but actually I don't feel like that!"

"I am very fortunate. Dan's kids have absolutely taken me with open arms, which has been amazing, and my kids have done the same with Dan."

She also has a great relationship with Dan's ex-wife. She can help with the other children at home, when Rebecca has to take one to an appointment in Hamilton, for example.

What are her aspirations for the children? "They can do whatever they want. I don't believe that disability is a stumbling block. We just encourage them all the time that they can be who they want to be," Rebecca says.



DANIEL SMITH

Being on the spectrum – along with his children means Daniel is uniquely placed to give these tips to those facing a new diagnosis.

These are his words:

From a parent's point of view – and as an autistic father with autistic children, I think the best advice I can give anybody is that you are the right parent for your child.

They are your child and nobody else is ever going to be a better parent for them than you are. It may be difficult and it may be hard, and things may not necessarily go the way you think they should go, but it is being a parent and being there for them and realising you have produced a child and you have to put whatever you want behind, and do the best for your child.

The best advice I can give anybody, is just to be yourself, realise what your limitations are, don't follow other people's expectations, and you need to find your own way about what is best for them and what is best for you.

You need to celebrate the differences and not worry so much. That is part of the diagnosis, being able to actually stop worry about fitting in with everyone else and realise you are not going to fit in.

Daniel Smith is a technical specialist in Immunohistochemistry at Waikato Hospital. He is a member of the Altogether Autism Consumer Reference Group.





KEEPING TIME: Tyler Bailey first starting drumming at 8 and now studies music at Otago University.

19 years on the spectrum. 11 years on the drums.



Tyler's introduction to life 20 days into the new millennium was traumatic, writes his father **Trevor Bailey** of Wanaka.

I've always been a believer if the talents for anything is there, nurture it.

A TWO MONTH early premature birth. Necrotizing enterocolitis (intestinal illness) diagnosis on day three. A race across Los Angeles in the early hours of the morning by ambulance with a team of medics from birth hospital to the Children's Hospital Los Angeles (CHLA). Two major surgeries and another two months in the neonatal intensive care unit (NICU). Amazing life-saving care. That was my son Tyler's introduction to life on 20 January 2000.

I often think about the amount of drugs Tyler received in those early months and the answer from a doctor when I asked what harm they could be doing long term. His response, 'they are keeping him alive today'. I could not argue with that!

From there two years of hospital visits, physiotherapy, and sign language skills.

Back to New Zealand just prior to his third birthday. Settling for a couple of years down south in Oamaru. Chosen as close to both sets of grandparents at that time. Christchurch and Dunedin.

It was clear to myself and my wife that something was up from early on. Tyler was non-verbal until just after turning three. He had a fascination as a baby with anything that spun. Walk into a big department store and he would immediately look for the ceiling fans. He could spin a quarter (25c) piece by holding with one finger and flicking with the other on his high chair table, kept him occupied for an age. Seemed cute at the time.

Autism or Asperger's had not been openly mentioned while in Los Angeles. The medical folk were concerned with his lack of speech and missing some of the growth indicators though. It was in early 2003 that Tyler was diagnosed almost immediately by paediatrician John Clarkson at Dunedin Hospital. Took him all of 10 minutes.

I remember leaving the appointment with my wife and Tyler trying to put a positive spin on what we had been told. I was familiar with the word autism but Asperger's in 2003 was a new one to me. I've never forgotten Dr Clarkson's words. Not to panic and that a large percentage of professors at any

university are likely on the spectrum and that's why they are so bloody minded and dedicated to what they do. Has always stuck with me that comment.

Tyler was then quite quickly involved with the Vera Hayward Clinic and I believe he was in one of the early intakes of the Early Bird programme in Dunedin. I think as a father my focus with Tyler has always been looking forward. I think it was during the Early Bird programme that Tyler's diagnosis really sunk in and potentially what it might mean for his future. One got to meet other parents with children under five all with different strengths and differences. I think as a parent of child on the spectrum you can't help but look at others and think "I wish my boy was doing that" or "wow I'm glad we aren't having that issue... now anyway!"

Over the years my wife Kathryn had lots of good advice from the Autlink Foundation in Christchurch whenever something came up. Very helpful.

I refer to what a nurse back in the NICU said to me one day in the ward where there were many children with many different issues, some that were visibly scary. She said, "yes others have issues different to your son but you need to just focus on what you are dealing with". I've always found that good advice.

A move to Wanaka in 2005 followed after Tyler had completed his first two terms of primary school in Oamaru. A new primary school and trying to make new friends after leaving the ones he had made at kindergarten behind.

As any parent of a child on the spectrum can attest primary school was/is an interesting mix of being your child's number one supporter, educating the school and obtaining support.

As a father it was tough to see my son struggling to have friends outside school hours. One particular day stands out for me. It was the school sports day down at the park.

I was there to watch Tyler from a distance. It was difficult to see all the other children having a great time in their little groups messing about and laughing. Tyler I could see was just wandering alone.

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I always understood it wasn't the other children ignoring him it was just that they did not know he would like to be included. The big thing I had come to realise was how invisible Asperger's can be to others. A new arrival at school, a great kid with a physical difference, had been immediately taken in by the other children. I made a point after this day of explaining this to the school which made some changes and developed a buddy system with Tyler and made staff aware to keep an eye out for what Tyler was up to at playtimes.

When Tyler was eight I was quite concerned and looking for an activity outside school to engage him. Sports hadn't really worked out. I happened to have a drum kit that I purchased in Los Angeles with good intentions to master. My wife had been introduced to Rhys a musician in town who had had experience with kids on the spectrum up in the North Island. So in August 2008 we gave it a go. At first I thought I was tossing my money away. Tyler could barely stay on the drum stool, falling off into the drums etc. But he did enjoy Rhys' company and Rhys certainly had a way in which to engage Tyler. So the deal I made was no Rhys next week unless you practice each day. That started with the egg timer set at five minutes. Once that buzzer went off Tyler was out of there. However slowly over the next year things started to click. Once I suggested to Rhys that he teach Tyler an actual tune he liked, things took off.

That song was Green Days '21 Guns'. By April 2010 it was time to get out in front of a crowd with Rhys on bass playing along Tyler on drums in front of three classrooms of his peers and their teachers, at Wanaka Primary School. That day changed so much for Tyler. You could see the looks on the children's and adults faces watching that they suddenly saw Tyler in a different light.

From that moment on Tyler really found his calling. Practice, practice, busking with an electric drum kit outside the New World and over the hill in Queenstown. Some public playing with other young ones around town. Lots of input from me to get these things happening.

Then it was onto Mt Aspiring College in 2011 and starting the whole process again with school, friends, teachers. Again it was the drums that made the difference for Tyler when he got to perform solo in 2012 at the school talent show in front of the majority of the school. He made his mark with both students and teachers that day. 2014 another performance opened the door for the formation of 'Near Armageddon'

Lessons lasted with Rhys until late 2012 when he moved from town back north.

From early 2013 until December 2018 Tyler and I travelled a five-hour round trip down to Gore each second Saturday over school terms for a two-hour lesson where Tyler was taught by Dean Ashby at the Ashby School of Music. Dean promotes and teaches the Rockschool format of lessons and exams. Over this time Tyler completed grades 1-8 with distinction passes. At the end of 2018 he sat his Level 4 Performance

Some highlights of his journey since 2013

- Two years running 2014/15 with his High School Band 'Near Armageddon' winning the regional finals of the Smokefree Rockquest competition. Once making the top 20.
- · Drummer for Mt Aspiring College Jazz Band.
- Travelling to Melbourne for the Australian Ultimate Drummers Weekend. 2013/15/16/18.
- Year nine and ten awards for outstanding contribution to music.
- 2015 Drumming for Dave Dobbyn at the YAMI showcase in Wanaka.
- 2016 Opening at Gibbston Valley Concert with Near Armageddon in front of approx 14,000.
- 2016 Drumming for Jon Toogood (Shihad) at YAMI again.
- 2016 Finals of the National Battle of The Bands competition in Auckland with TeHight a band of adults he played with for a year or two.
- 2017 Senior Music Award and Scholarship. Mount Aspiring College.
- 2018 Tyler managed a three week solo trip back to Los Angeles where good friends looked out for him. Lots of drum-related activities.
- 2019 Tyler made an Australian Music Examinations Board Rockschool Ambassador.

Exam and gained a distinction pass in that too. All exams were taken by overseas examiners.

We also regularly travelled to the Dunedin Musicians Club where Tyler was immediately accepted and spends many hours on stage there now.

I often struggled that Tyler not once over his high school weekends was ever invited to a party or out. Or that he wanted to go out. The drum room was and still is his place for 2-4 hours practice and the Asperger's is what has made him as good as he is.

In summary it's been huge in both time and finances and a lot of it likely would not have been able to happen had Tyler had any siblings. Once I saw Tyler's potential I just had to give him the opportunity. I've always been a believer if the talents for anything is there, nurture it. Tyler has this year started studying at Otago University for a Bachelor of Music degree with a minor in writing. Something both my wife and I could not have imagined a few years back.

I hope that Tyler's story helps anyone out there looking for an avenue for their child. There is so much more to Tyler's journey as there is with everyone's.

Trevor Bailey is a certified massage therapist in Wanaka.



COUNTING THE BEAT: Tyler Bailey drumming with Near Armageddon in Gibbston Valley, Central Otago, 2016.

Facebook link: www.facebook.com/Tyler-Bailey-Drummer-387648594706405 Rockschool link: rockschool.ameb.edu.au/ambassadors

Enlightening education journey defies predictions



Ask **Tahuaroa Ōhia** to describe the relationship between his father and him and the word taonga springs readily to mind. Altogether Autism delves into what he means.

HAMILTON AIRPORT seems an odd place to meet to talk about the relationship between Wellington-based father and son Bentham and Tahuaroa (Tahu) Ōhia.

But the opportunity to chat to them face to face about what is clearly a special bond is too good an opportunity to miss.

It was the 50th birthday party for Bentham's brother that brought the whānau – wife Kate Cherrington and daughter

Tuakoi, 23 - back to the Waikato for two days from Wellington and Auckland respectively.

They are a close-knit family unit clearly proud of Tahu, 20, who was diagnosed with autism when he was six, back in 2005.

The diagnosis came the same year Bentham took up a job as Te Wananga o Aotearoa chief executive in Te Awamutu. The family were living in

Tauranga at the time and the challenges of a new job meant his availability to participate in the many meetings needed to establish a route forward for Tahu were limited.

Bentham had no idea what autism was when the diagnosis came. "I didn't really understand what it was at the time. But then gaining an understanding of it made me think about a lot of people I met in my life who had similar characteristics



LOOKING BACK: Tahuaroa Ōhia with his sister Tuakoi and mother Kate Cherrington.

so it raised my consciousness around wanting to, with Kate, Tuakoi and whānau, create pathways that would be more enlightening for Tahu."

It was the empowering role education has which became important to Bentham and Kate for Tahu as they are both committed to education as the answer to life. They work in it and their opinions are readily sought by sector groups and politicians.

Tuakoi knew her brother was unique from other kids. "When I was younger it was a bit hard for me to understand him. Once he was diagnosed, that didn't change the way I saw him. I've always been protective of him."

Giving Tahu the opportunity to shine and rise above the challenges life as an autistic represents is something Bentham valued then and now and is something Tahu values in his father.

"I really wanted my Dad to get to know me a little bit more, but he has to try and put food on the table and clean the car etc.

"That was sad because I really wanted him to be part of our childhood, he was just far away.

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"Give him credit. Some other

dads would want to get out of

this commitment... there are

some parents who are useless

and there are some that are

natural. Dad's a natural."

WHĀNAU TIES: Bentham, Tahuaroa and Tuakoi Ōhia with Kate Cherrington.

His body was in another place, his spirit, his wairua was definitely there for me though. With other fathers, they would want to take their presence and spirit with them.

"Give him credit. Some other dads would want to get out of this commitment. I don't really know what other dads think about autism there are some parents who are useless and there are some that are natural. Dad's a natural."

The two have their differences. Tahu is into cult geeks, comics and movies. Bentham loves his rugby and helping communities.

Asked what advice he would give to other fathers struggling to understand autism and how to respond, Tahu says: "Don't be scared of your kids because what you made right there is really special. You made a taonga. Give (your relationship) a try, don't walk away."

Seeing this confident, well-spoken young man now and it is hard to visualise him as a child whose only way of communicating was by using a single word, Rex. The answer to every question was Rex.

Tahu's brain was processing plenty though. He knew all the words and actions in the American animated science fiction film The Iron Giant. He mimicked the character's movements at every opportunity. He was into dinosaurs; hence he loved the word Rex as in tyrannosaurus rex.

"I didn't know how to spell hello, which was really unusual for the teachers, or goodbye, or how are you doing. I did not know how to put them into sentences.

"Teachers would say: 'Can you spell a word?' I'd just spell Rex, because I'm into dinosaurs."

He was fluent in Te Reo Māori though.

"I wouldn't say I was different, but I would say I was an unusual human being, alien, monkey whatever you want to say."

He pays credit to his family and teachers for their support.

"I had a lot of help from teachers, I did have a lot of help when my Mum said I was diagnosed with autism, they had to get to know me first and then put me in a space where I could be myself around other kids. I did scream, I did kick, I did push away some of the kids back in the day. I didn't want to hurt them like the Hulk. I just wanted to be left alone in my own world. I just wanted to protect myself in my own world."

The pursuit of education became a driver for him particularly because some teachers and doctors said they did not know if Tahu was smart enough to get through school or would have to be held back in class.



FATHER-SON: Bentham and Tahuaroa Ōhia.

Today he is two years into a diploma in performing arts at Te Auaha Whitireia in Wellington. Once he gets his diploma, he will switch and study musical theatre aiming to get a bachelor's degree so he can become an indigenous film director. He wants to put indigenous people into short films to learn about their histories, their stories.

"Achievements are not a one-time thing. Every challenge has an achievement and every achievement doesn't come once, it comes in many ways. You can achieve by opening a jar."

Autism is who he is, says Tahu.

"To be honest, I'm happy. I know I had a rough childhood trying to get through this challenge, trying to process my brain.

"Guess where I am right now. I'm still going through challenges with my autism at school and at home. But at least I got through them. There are heaps of challenges out there.

"I did achieve. I achieved on speaking, on trying to communicate, but the really cool thing about achievement is I'm still alive today. If I fail, I still get through the day."

Tahu's tribes are Ngāi Te Rangi, Ngāti Pūkenga (Mataatua Waka) Ngāti Ranginui (Takitumu Waka), Ngāti Te Roro o te Rangi (Te Arawa Waka), Te Āti Awa (Tokomaru Waka), Ngāti Rārua (Tainui Waka) and Ngai Tahu (Takitumu Waka), Ngati Hine, Nga Puhi and Ngāi Pākeha.





IN PURSUIT OF TE REO: Tahuaroa and Bentham Ōhia are both on an education journey.



Journey of discovery for Taylor family



Some parents struggle with having one autistic child, consider what it must be like having five. **Altogether Autism** talks to a Waikato father about how he is blessed to have five

WHEN DAVID TAYLOR talks about his children, be prepared to go on a journey of autism discovery.

All five of his sons are autistic and each is quite different, plus, about three years ago, David himself was diagnosed with high-functioning autism and 13 years ago diagnosed with dysgraphia (a neurological condition where a person has difficulty with writing).

Under emotional and academic pressure, the 50-year-old Auckland-born house husband struggles. He cannot spell and his writing is poor.

"I'm like a really messy filing cabinet. My thought process is different, it takes a little bit longer for me, but I get there," he says.

He needs to "get there" because the challenges he and his wife Justine must deal with daily, would test even the most efficient or methodical person.

"Look, don't get me wrong. It's been a fantastic privilege to have my children. We are blessed."

Wind the clock back and David is 15, living on Waiheke Island and about to drop out of high school with no qualifications. His family life was dysfunctional, both parents were alcoholics and one of his three brothers had attention deficit hyperactivity disorder (ADHD) which resulted in him taking his frustration out physically on David.

David met and fell in love with Justine as a teenager. They split and went on to marry other partners. Justine had two boys – Matthew, 19, and Hayden, 14 – both on the spectrum.

Before David married, unbeknownst to him until some years later, he had a son, Jonathan, now 28, on the spectrum, and living in Christchurch.

His only son from his first marriage, who won't be named, is now 18 and a high-functioning autistic.

Both marriages broke down and the childhood sweethearts found each other again, married and nine years ago had Benjamin, who completed the picture by also being diagnosed as autistic.

"We're a blended family. It's fair to say life's a little complicated."

Three of the boys – Matthew, Hayden and Benjamin – live at home with David and Justine in rural north Waikato.

Justine is often away from home as she works as a facilitator, providing professional development (including special needs and literacy) for teachers and schools across New Zealand.

David's main interests outside of his family are martial arts – he has a taekwondo black belt third degree – and mentoring.

The constant battles with various services, organisations and people who view David and Justine as "atypical parents with atypical personalities"

means life is never dull.

Battling with multiple organisations for each child to gain support became exhausting and traumatic. Repeatedly retelling their story, coordinating appointments, sitting on waiting lists for lengthy periods, experiencing judgement from professionals, lots of talk around the table resulted in very little practical support. David feels the turning point came when both Justine and David made the decision to disengage from these organisations to manage the boys themselves.

"It can be tough at times but there is hope. Our kids get to a good place in their own time and in their own way," says

Removing societal expectations/pressures is vitally important for neuro-diverse people.

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"It can be tough at times but

there is hope. Our kids get

to a good place in their own

time and in their own way."

"Life becomes easier when we allow our family to develop at their own pace."

David supports the boys with their daily life by advocating on their behalf. This includes engaging with doctors, chemists, teachers and the world when out in public.

"While advocating for our children in schools is challenging as you become labelled as a difficult parent very quickly, it is important to remain an active advocate throughout their schooling as they need you to do this within our current school system."

David emphasises that Justine's support to understand how schools and teachers work has been invaluable in making advocacy with schools successful.

"It is very important to build respectful relationships and work collaboratively with schools while advocating for your child."

In 2018, Hayden and Benjamin both started at Whitikahu School, northeast of Hamilton, a 90-roll country school for years 1 to 8. (*see Education Review Office comment below).

"They have been amazing. They provided an environment for Hayden to succeed and now Ben is flourishing there as well.

"Talk about relationship building, they are just a wonderful, inclusive, community-based school. Everybody helped."

Matthew left high school when he was 16 unable to get anywhere in the system even though he won a cyber security competition at 15 and was awarded a full scholarship through IBM to attend Unitec.

He now works for a computer technology company and is totally self-sufficient financially. He has many online friendships and work connections with people from all over the world. Conscious of the lack of public transport in rural Waikato, Matthew is concentrating on getting his drivers' licence.

"That will be yet another challenge," says David.

Ben is the family 'social aspie' - incredibly active and chatty.

"Our mantra at home is 'Change is Constant – we can't fight it.' The only thing you have control of is yourself."

The boys need David to walk them through change and support them with this.

He is concerned about how young men generally are being taught not to be caring, to harden up, to shape up.

"I teach my men to be kind, considerate and nurturing and that it's okay to touch. Touch is important. I teach them mindfulness.

"Hope is the main message. The world is changing, your children become adults and successful adults in whatever way is successful for them."

Top tips for fathers with autistic children

- Don't take crap but be polite. Make notes, stick to your notes.
- Patience, patience, patience.
- Look after your own relationship with your partner, take micro moments.
- Engage with schools at every opportunity, whether they like it or not.
- Every time they bat something at you, bat it back with: "I don't think that's my role as a parent, it's your role as a teacher".
- Remember to look after yourself. Take the time.
- Don't worry about what's happening now, things will change.
- It might be hard today, but it will get better tomorrow.
- You can't always protect your children.
- You're there so when they fall over, you can pick them up and put them back in the world.
- Ask for help if you need it, approach every agency you can. Not every agency is the same. Never stop asking.
- If you run out of energy get someone else to help if you can so you can recharge.

David Taylor is autistic and a north Waikato-based house husband with five sons.



DOG GONE: Great Danes Ava and Noah are great companions for David Taylor and his family.

Students with additional learning needs are well supported. Systems for the monitoring and tracking of students are effective. A knowledgeable special educational need coordinator (SENCO) works cooperatively with staff to provide a range of effective interventions to respond to at-risk students' needs. The SENCO accesses specialist services for children with additional learning and/or behavioural needs. Parents are well engaged as partners in their children's learning. – Education Review Office, 2019.



The Family Court and families who have members with autism



Clinical psychologist **Kathy Orr** has worked in the Family Court for many years and is well placed to discuss fathers who have autism and their experiences of parenting.

I PREPARE assessments for the Family Court when parents cannot reach agreement about their child's care arrangements after the parents separate; or when a child has been removed from their parents' care due to concerns that the child's care is not meeting their needs. I also provide some counselling for distressed parents following their engagement with a Judge who is likely to have made orders with respect to future family arrangements.

I note here that I work at the highly distressed end of the Family Court and for some people reading this, you will think that I am over-exaggerating. I assure you that all comments are taken from families I have had the privilege of working with

I also note that many parents separate and sort out their child-care arrangements with no or little intervention from anyone. One thing I celebrate is today, more fathers stay involved with their children post-parental separation.

Children do best when they have both parents and their extended families involved as the child matures. We call this the child's "social capital", the people who are available to celebrate with and support the child through life's ups and downs.

I am going to speak to some of the issues that I have encountered when meeting with families where one (or more) members have been diagnosed with (or have not been but show traits of) autism. This article takes the worst scenarios as this allows for discussion of how to make changes or what to do if you are in this situation.

I start from what I call the "bad", when the family separates and issues around this. I then move to trying to promote healing with some tips for the future. The future is there, and we must believe in one step at a time to get there.

Children do best when they have both parents and their extended families involved as the child matures.

The breakdown of the relationship

Families who come to see me within my roles in the Family Court are distressed and often really struggling with what has happened to them and their family members. For adults on the spectrum, their natural emotional loss and processing is compounded by the legal process. Parents fear loss of their children and are often grieving for the loss of their relationship with the other parent. The implications of all this loss and court process can be overwhelming. Routines and certainty have been shaken up. Some people have described this as being like a "freight train has rolled over me, and I am in a new (unrecognisable) world."

There can be allegations made by the other parent which seem unfair. This can be a recipe for disaster.

Parents are vulnerable and defensive and there can be the start of a fire which burns and the child and their best interests are forgotten. For parents with autism, their vulnerabilities are exposed, and this is a time of feeling alone and isolated.

As I look back on relationships, I can observe that one parent has often been unhappy for about two years. When the separation comes, it is about finding a reason to create a crisis and blame (in an unhealthy separation). To have your partner diagnosed with something, including autism, can then shift the blame from the other parent.

Diagnosis

The diagnosis of autism can be difficult to achieve and for some families in stress, such a diagnosis coming on top of the stress can create a breaking point. I have had several couples come to see me when the relationship is not working and thinking that one partner has autism.

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This may be the case. If so, this can be positive and a few couples have moved forwards positively into the future.

However, for more than half (my guess) this has signalled the end of the relationship and become part of the later claim and counterclaim. It's as though the person with autism is somehow a lesser parent who can be marginalised, which as we all know is not what is fair or needed for the children.

The children

Imagine being a child, and then add being one with autism, who has relied on their parents to provide their routines and stability, consistency and predictability. You are suddenly exposed to chaos and arguments; or the "silent" treatment. Parents are fighting about the children, money or lack of emotional comfort. Children come to believe that it is their fault that Mum and Dad are not getting on i.e. "Without me, they would not be unhappy, they would not have separated. It's my fault." Adults call this "magical thinking" but there is a certain logic here.

One parent then is missing and the other is not parenting as before (the parent who cares for the child/ren often has a period where they are more self-focused and not as responsive).

Your brother(s) and sister(s), if you have some, may help and try to provide for younger children, but you might be the oldest and therefore see yourself as responsible.

The perfect storm

There is now a disrupted family, with the pieces now an incomplete whole.

Both parents say that they love their children. I am sure this is true. However, I note that the adult behaviour does not always show this love and support that the child's interests and needs are primary (as required by the Family Court laws).

Both parents are angry with the other who has let them down. They find fault in the other and blame them for all events that have happened. The story of the relationship is rewritten. This anger can become revenge and hatred. Imagine being a child in this "war zone".

Parents involve their family and friends. Sometimes if you as family and friend do not support the hurting parent, you become part of the calamity and excluded from the life of that parent and the child/ren.

This is a time of high emotions which can lead to the making unfounded allegations and seeing things that may not be there. These communications can escalate the situation to a win-lose position and who will "own" the child/ren.

If your child has autism

In my experience all children do better if they have the support, care and parenting of both parents. Generally, most children (neuro-typical and others) do best if they have what is called "authoritative parenting": a mix of love, nurturing, boundaries, routines and consistency, predictability and a parent who understands their child and varying moods and behaviours. There is no magic middle point of this parenting style but trying to meet the child's needs is the most important thing to do. For a child with autism, I would respectfully suggest that the needs outlined, especially the consistency, predictability and routines are most important.

This means that both parents need to work more cooperatively together to ensure that their child's needs are met. This is not one parent being dominant and taking control.

Equally, there may be an argument for the child to have a more primary-secondary home relationship than an equal shared care arrangement, but this will be on a case by case basis.

Both parents need to ensure that the other is involved in any professional appointments for the child e.g. school, therapy or intervention strategies, medical. It is important for the child that similar (as same as possible) routines occur in each home (sleep, meals, taking account of any sensitivities etc).

Do not involve the child in your new family too early. Your child is struggling with the separation of their primary family. Step-parenting is an art, and because your new partner is a good person for you, does not mean that your child will like them.

Tips

- 1. If you are the parent who is left (often without the child), take a deep breath and allow yourself to grieve. Do not look for what has happened. Look to celebrate that you have a child.
- 2. Find support. Ring up your best friend, a parent.
- 3. Take a sick day/ week from work. Tell your employer/ boss what has happened.
- 4. Cry, feel angry, feel confused.
- 5. Take a walk and look at nature. It's beautiful at any time of the year. I love to walk on a west coast beach in winter as it clears my brain cobwebs out.
- 6. Create your routine and get your body back into "normalcy". It will be a different "normal" but this is now the future.
- 7. Write an email to the other parent and ask to catch up with the children. It is important for the children that they keep contact with you as you are part of their social capital.
- 8. In a separate way, ask the other parent if they will go to counselling, or meet with you, to talk about what is happening and future arrangements. Maybe there is a trusted mutual family member who could meet with you both (as a middle person).
- 9. To save later misunderstandings, write down and both sign any agreements. There will be compromises needed, which are hard to think of when you are also hurt.
- Maybe think about getting professional support if you are not getting any visits with the children and feel you are being excluded; or you feel overwhelmed by your emotions.
 - a. Lawyers (look for those with Family Court experience) are good with making legal arrangements and talking about ways to go forward.
 - b. Counsellors are perhaps better at helping you with how you are feeling, though those with Family Court experience will also be able to suggest ways to go forward.
 - c. There are a small number of psychologists who, most like me, are over-committed to current and future work. We are the people who provide the specialist reports to the Family Court. If you are a parent or with a child who has autism, let us know and going forward, arrangements can be considered in the process.

Kathy Orr has been a clinical psychologist in Hamilton since 1980. Her areas of interest include working with people with disabilities especially intellectual and other conditions with this as a factor; and people who have autism.





Mothers and fathers play an important and meaningful role in the upbringing of their children, writes researcher **Emily Acraman**.

The ways mothers and fathers communicate and interact with their children are unique and can look quite different from each other.

PARENTS EACH have unique ways of talking, playing and interacting with their children and both parents provide an important contribution to their child's development.

While traditionally most of the literature concerning child development, autism, and the role of the parent is focused on the mother-child relationship, there is growing research that examines the unique contribution of fathers.

What this literature tells us is that in general, high quality father involvement in a child's life is a strong predictor of better development outcomes, including improved emotional regulation and cognitive and language development (Flippin & Crais, 2011).

Of interest, is the difference in ways in which mothers and fathers interact and communicate with their children.

Fathers show several differences from mothers in communication and language styles, and these differences are thought to directly impact children's language development.

As one of the defining features of autism spectrum disorder involves difficulties in communication and social interaction, research tells us that further exploring and understanding the unique role fathers play in their child's communication and language development may lead to improved outcomes for children and service providers (Flippin & Crais, 2011).

What the research says

Research involving 'typically developing' children has established that fathers have a unique way of communicating with their children.

Fathers generally use a more complex, higher level of vocabulary and are more directive with their communication than mothers. For example, fathers have been found to use more complex 'wh' questions, whereas mothers tend to use more yes/no questions (Flippin & Watson, 2015).

As a result, children tend to use a higher level of language with their fathers than they do with their mothers which has been found to have significant benefits for later language development.

Pancsofar and Vernon-Feagans (2006) found that the language fathers used with their child at two years old significantly predicted levels of their child's expressive language one year later. While mother's language use on the other hand, did not offer the same level of significance (Pancsofar & Vernon-Feagans, 2006).

It has also been shown that children experience more "communication breakdowns" when interacting with their fathers; most probably because of the higher level of language used.

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These communication breakdowns are important as they provide the child with an opportunity to communicate more coherently and to clarify or fix-up misunderstandings.

Essentially, these complex language characteristics associated with father-child interactions are thought to better prepare the child from the transition of the supportive language experienced at home in the early years, to the more complex linguistic demands of the 'outside world' (Gleason, 1975).

Research involving father-mother differences in communication models with children with autism is limited.

However, findings suggest that the unique father-child exchanges demonstrated with typically developing children may also support communication development for autistic children.

Interestingly, studies comparing the parent-child interactions between groups of parents with typically developing children, and parents with autistic children revealed there were very little differences between the two groups.

Rather the differences in communication styles was experienced most significantly between mothers and fathers.

While mothers tend to be more conversational; using more requests and more statements, fathers engage in more 'other behaviour'; sitting quietly, laughing etc. (Wolchik, 1983).

It has also been found that mothers and fathers in their interactions with their children ask an equal number of questions, but fathers use a smaller percentage of prompts and statements and use more directive questions (Konstantareas, Mandel & Homatidis, 1988).

Another difference between mothers and fathers and their communication styles is their responsiveness to their child's behaviour.

Parent responsiveness can be defined as the way a parent reacts both verbally and non-verbally as a direct response to their child's behaviour and communication.

Studies examining parent responsiveness conducted exclusively with mothers have shown that higher maternal responsiveness is a predictor of better language development for children with autism.

Flippin and Watson (2015) examined the differences in parent responsiveness between fathers and mothers with their children with autism.

They showed that mothers were overall more responsive than fathers to their children. Also, children tended to show stronger language skills when both mothers and fathers used more verbal responsiveness.

Interestingly however, only father's verbal responsiveness was significantly associated with child language scores.

Thus, even though as a group fathers were less responsive than mothers, the variability in father's responsiveness had a stronger association with child language levels.

These findings demonstrate the strength of the father-child communicative relationship and its significance to child language development.

It also tells us that while mothers may engage more with their children, and be more conversational, the contributions of fathers are not less important than those of mothers (Flippin & Watson, 2015).

Summary

The ways mothers and fathers communicate and interact with their children are unique and can look quite different from each other.

While typically fathers tend to be less responsive, more directive, and less conversational than mothers, research tells us these unique aspects of father-child communications may indeed play an important role in supporting a child's communication and language development.

This may be particularly important for children with autism who have difficulties in these areas.

Understanding and further exploring the differences in interaction and communication styles between mothers and fathers is important for future research and for interventions that target communication difficulties for children with autism.

By involving fathers more in these areas, we can maximise opportunities for social-communicative gains for children as well as supporting and encouraging the unique contribution of fathers.



Emily Acraman is a researcher at Altogether Autism.

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Welcome to Michael's wonderful world



Michael Woods parents knew he was not your run-of-the-mill kid even before he started primary school. His mother **Elizabeth Woods** tracks his journey.

It has been a struggle for acceptance, a struggle for recognition and kindness, a struggle to be embraced for all his brilliance, despite the fine print that Asperger's brings.

THIS IS MY SON Michael. Michael is in his second year of a History degree at the University of Canterbury and he is happily smashing it out of the park. He has a staggering intellect, a photographic memory that lets him memorise textbooks and everything he reads or sees, a fantastic and quirky sense of humour, he is a very talented actor, rock drummer, playwright and a passionate and incredible film maker. He has a great group of friends and a great social life. He is gentle, kind, empathetic, talented, charming and caring.

And Michael, 20, has Asperger's Syndrome.

Following his submission of an abstract, Michael has just been accepted to present in person at the 13th Europe Autism Congress in Nice, France in September.

This is an international conference that only happens every three years and it's an honour for him to be selected. Michael is going to talk about his film making, his journey with coming to terms with his Asperger's, his realisation that it gives him a creative way of looking at the world and his acceptance and embracing of what he now sees as a superpower.

This is a huge deal for Michael and an incredible opportunity. An international conference with experts from all over the world, and one special young Kiwi who will stand up in front of hundreds of people and open up about his life and his own journey.

Michael is also one of the bravest people I know; he has not had an easy road. It's been a lonely one, fraught with all kinds of obstacles and battles. It has been a struggle for acceptance, a struggle for recognition and kindness, a struggle to be embraced for all his brilliance, despite the fine print that Asperger's brings. It's been a struggle for him to be able to show his true self and overcome the prejudice and misconception that an Asperger's label carries.

Before Michael started school, we knew that he was not your run-of-the-mill kid. He didn't talk until quite late but when he did he could mimic any accent. He was obsessed with trains and history and couldn't handle loud noises or crowds. He hated pre-school and I was regularly called to collect him as he got so distraught with the chaos that can be a kindy playground.

Once he started primary school it became very clear that he was different and the boy he was at school was very different from the one he was at home. At home I had a sparky, interested, super bright kid and at school he was quiet, frustrated, upset and often angry. The teachers didn't understand him or Asperger's and despite my assertions that he was incredibly clever, they wrote him off as having a 'developmental delay' even going so far as to say to me 'I'm afraid he will never amount to much intellectually'. They couldn't have been more wrong.

When he went to intermediate and moved into a discovery self-directed learning environment his true nature suddenly became very apparent in a spectacular way. I was accustomed to receiving phone calls from school and my heart would sink when I saw the number come up on my phone. This time however the teacher sounded bemused – could I come in for a chat? Michael had only been at the new school for a couple of weeks and was still an unknown quantity.

At his previous school, during writing time he had been told he had to draw a picture and write a paragraph and so, as an Aspie and someone who wanted to follow the rules he did exactly that, drew a bland picture and wrote a paragraph. This time, when asked to do some writing, Michael asked the teacher how much they wanted him to write. The teacher told Michael that he could write as much as he wanted, about anything he wanted. "Really?" replied Michael who was genuinely surprised at the sudden freedom. "Can I write through lunchtime?" he asked and the teacher gave him permission to do just that.

I visited after school had finished for the day and his teacher sat me down and showed me what Michael had written – a five-page history essay on the assassination of Arch Duke Franz Ferdinand that precipitated WW1, the social and political fallout of this action and a suggested alternative world history if the assassination had not occurred. It would have done a first-year university student proud and to say I was gobsmacked was an understatement.

Michael had two great years at that school and then started high school which was the beginning of an appalling two years in his life.

The teachers didn't understand him, belittled him, refused to accelerate his learning and forced him to study subjects that were years below his level. He was bullied unmercifully by other students for being clever, for being different, for being red headed and the school did nothing about it. He was threatened and monstered on a daily basis, followed after school, threatened with being shot by a classmate's older brother and on one terrible occasion, set upon by a bunch of the older brothers of one the school's worst bullies – within sight of the school gates. During those horrible two years the school did nothing, despite my almost daily emails, calls to the police and pleas to the Board of Trustees.

On one memorable afternoon when Michael tried to tell the vice principal that he had a photographic memory and had already memorised a book he was being made to read repeatedly the vice principal said to him: "Well that won't be much use to you in later life will it?"



BEHIND THE SCENES: Michael with his camera, the one I used to film 'The Parcel'.

During this awful time our lovely stone house on the hill was badly damaged by the earthquakes, we shifted five times, and we had years of fighting the earthquake battle that so many Christchurch homeowners suffered through.

After realising that Michael was almost at breaking point, I pulled him out of that high school and made the best decision I have ever made for him in my life – I managed to enrol him at Ao Tawhiti Unlimited, a Christchurch special character state school with a fundamental tenet that the child is central in directing his or her own learning.

To say that it was the making of Michael is a huge understatement. Ao Tawhiti is heaven for a gifted person. It was an unbelievably fantastic environment for him and the school, rather than seeing his intellect as a hindrance, celebrated his amazing ability and gave him the freedom to go as far and as fast as he wanted, with stellar results.





LIGHTS, CAMERA, ACTION!: Poster and stills from Michael's film 'The Parcel'.



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Within two years he passed NCEA levels 1, 2 and 3 with a raft of Excellence passes and attended Uni as part of the Star programme at 17, studying and passing stage one psychology. He started acting, writing plays, studying philosophy, sociology, history, film studies, reading voraciously, becoming an accomplished rock drummer and making some great friends.

Michael had shown a keen interest in film making and after seeing a 10-minute film he made using the school camera and realising that he was serious about film and had talent to go with that passion, we bought him a decent camera for Christmas and he told us he was making a film.

Over the next few months he squirreled away at it, with he and his older brother doing the acting, a couple of his school friends holding microphones, doing some filming and the rest of his family being called in to do some special effects with fishing lines!

Throughout the time he was making it we weren't allowed to see any of it, as he wanted to present us with the finished product.

Then he announced that he had finished, the film was 30 minutes long and we sat down to watch the finished product.

As the film started and the story unfolded, we were stunned. The cinematography, the narrative, wonderful awkward vulnerability of the character he was acting

were all communicated is such a heartfelt way and as I finished I found myself crying at what he had achieved.

"I once asked him, if he could wave a magic wand and not have the Asperger's would he do it? 'No way' he said – "it's my Asperger's and if I didn't have it, I couldn't see the world the way I do, and I wouldn't be me."



There was one particular scene where he had created in film the character experiencing a panic attack, and it was so real you could feel the fear and disorientation.

The film was so very good – quirky, funny, moving, charming and we were left speechless. He had created a little masterpiece of semi-autobiographical magic, a

whimsical interpretation of his own struggles with his anxieties and fears and his eventual overcoming of a burden he had been carrying.

The film follows a young recluse attempting to deliver a mysterious parcel and in doing so facing his fears and discovering his own self.

When an academic acquaintance suggested that Michael submit an abstract to the 13th Europe Autism Congress we never dreamed he would be accepted, there were people from all the world submitting, so we were in a state of shock when he received the email inviting him to present. We are now frantically rushing about trying to fund and organise a trip to France!

At his graduation from Ao Tawhiti, Michael was one of two graduating students to make a speech and he spoke with eloquence and honesty, to resounding applause.

His learning advisor spoke about Michael and said that in a long teaching career you come across only one or two students who stand out and who you know are going to shine brightly and make their mark. He said that for him this was our Michael.

He is a humble guy, who doesn't make a song and dance about himself, he just gets on and does whatever he wants, with a minimum of fuss, not believing for one second that his Asperger's limits him in any way.

I once asked him, if he could wave a magic wand and not have the Asperger's would he do it? 'No way' he said – "it's my Asperger's and if I didn't have it, I couldn't see the world the way I do, and I wouldn't be me."

I want people to know about Michael and his story. I want him to go to that congress knowing that there are people in New Zealand cheering him on, knowing that he isn't limited by what so many people see as a disability, knowing that he can shine as bright as he can without any limitations.

I want to see him stand up on that international stage and proudly tell everyone "Hi, I'm Michael Woods from New Zealand and I have Asperger's – isn't that wonderful? Welcome to my world."

Elizabeth Woods is a senior trustee at Public Trust in Christchurch.



MOTHER AND SON: Michael Woods and his mother Elizabeth

All aboard for a magnificent fishing trip



No amount of planning and organising could have set whānau up for such an amazing family filled day of fishing, writes Jane Ford.

AS ALWAYS when dealing with humans, all good plans go out the window in the first five minutes.

On board ship, 11 fathers or uncles, three mothers, 20 children, captain, four deck hands, and myself on our annual fathers fishing trip, this time with Blue Ocean Charters.

The 'Dads and Kids' fishing trip on Saturday 16 February fast tracked into to a family event as three beautiful mothers looked longingly at the boat. After a quick vote, they were were let on board.

Next plan, to stay in the Tauranga Harbour but with the weather and conditions being amazing we headed out to the marker 'A Buoy' and then onward for a three hour round trip for a picnic tea at Matakana Island after fishing out towards Mayor Island.

Blue Ocean Charters owner Rachel Ensor and skipper Tom Mayne were amazing. They provided us with double the deck hands so that the parents could enjoy themselves, rods for all, bait, lollies, a turn at being captain and driving the boat for each child, loads of smiles, an opportunity to make some special friends, share stories and mostly just to step off the treadmill for a day and enjoy being a family and connecting with others who understand.

For a lot of these families it was a mahara they will treasure.

Thoughts for next year, if we are lucky enough to be able to repeat the experience, is to split the funding over four smaller trips to include more families, including a ladies trip, and one leaving from Opotiki.

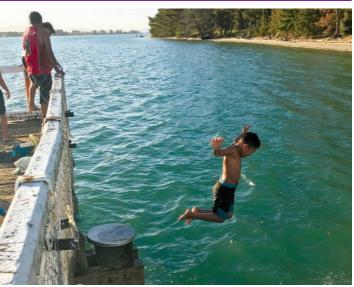
Jane Ford is the Coastal Bay of Plenty regional coordinator for Parent to Parent and Altogether Autism.





GONE FISHING: Travis Rahmann with his daughter Maecy, left and right Jackson Brown holds the steering wheel as they enjoy the day-long fishing experience.

"Trip was a trip of a lifetime for our family."



DIVE IN: Wihau Rapana jumps into the water while Nevaeh Martin behind him waits to jump



Is there an autistic child in your life?

Look out for our FREE workshops for family/whānau and professionals

Coming to your region soon



Workshop: "Kids do well if they can"



Dr Ross Greene

- Drawing from a collaborative and proactive solutions approach developed by American psychologist Dr Ross Greene, pictured.
- Includes takiwātanga (in his/her own time and space), excecutive function and theory of mind from a strengths-based approach.
- Facilitated by autism specialist facilitators.

Free to attend and includes light refreshments
Dates and venues on our website
www.altogetherautism.org.nz/events
or Like us on Facebook and follow
altogetherautism

