

# A WORLD — OF — POSSIBILITIES

*Where there are dreams  
there is hope*





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*A World of Possibilities* is dedicated to the families and young people who  
shared their inspirational stories with us.

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**Editor**  
Sue Pairaudeau

**Design**  
Steven Mahoney

**Editorial**  
Sue Robertson  
Clare Chapman

**Photos**  
Melissa Palmer / Nectar Photography  
Stellar Management  
Sue Pairaudeau  
Steven Mahoney



# A WORLD OF POSSIBILITIES

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**This is the story of how being surrounded by abundant love makes a great future possible for children with disabilities.**

The vision of what makes life good is different for every individual and family.

Regardless of disability, young people with gifts, skills, talents and a huge capacity for contribution, friendship and success, want what all other young people want – to laugh, play, study, train, live independently, engage in meaningful employment, and have a say in their world.

Just like any other child, with family understanding, respect and trust, these aspirations can become reality and their futures full of hope.

# Being 'just Bailey' is who she is

by GWEN MATCHITT

**B**ailey is the youngest of four children, and turned 10 on May 30, 2017.

I was 42 and a bit shocked to find out I was pregnant. We all had to adjust to the fact that our family of five was going to expand. But by the time Bailey was born with the attributes of Down syndrome, Jayden was able to sum it up for us: "She's my sister and that's all that counts."

Bailey arrived in this world with some already established roles – her place in our whanangatanga means she's a much-loved daughter, sister, granddaughter, cousin, and she's now an aunty for the first time to her nephew Karmelo.

She is well known in our community, at school, around our netball courts and at the supermarket. She's been

part of all our family activities and gatherings. She's 'just Bailey', and right now she's cheeky and lovable.

Bailey loves music and since birth has been surrounded by music of all genres; she loves the drums and to dance. She loves running and especially swimming. Noisy environments can upset her. She's someone who enjoys her own company and we think that coming from a sporting family, in the future she might be supported to explore individual sporting pursuits rather than being part of a noisy team. Having said that, she's been brought up in the netball community and loves running around with the other kids at the courts.

Being 'just Bailey' means our community is learning all the time about embracing diversity. Our whanau's openness about who

A portrait of a young woman with long dark hair, wearing dark-rimmed glasses and a grey sweater. She is smiling slightly and looking off to the side. The background is a green lawn and a wooden fence. The name 'Bailey' is written in a white cursive font in the top right corner.

*Bailey*

Ko Bailey Phillipa Matchitt toku ingoa. Ko Lance Matchitt toku papa.  
Ko Gwen Matchitt toku mama. Horouta te waka. Te Whanau a Apanui te iwi.  
Te Ehutu te hapu. Kaakanui te maunga. Materuia te awa. Te Kaha te marae.



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Bailey is has supported others to be more open about their disabled family members. I know it.

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WE CAN SEE BAILEY WORKING  
AND GETTING ON WITH THE USUAL  
DAY-TO-DAY STUFF THAT THE  
REST OF US ARE INVOLVED IN.

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I believe that having a good relationship with people in the

education system is critical. So far Bailey has gone to her local kindy and primary school and learned alongside her peers, with support from the education system.

I've had to be an advocate for her so she can access what the system is able to provide. Bailey was enrolled at kindy for a short time to enable her to meet the eligibility criteria for enrolment in the school of our choice. This school has no barriers to inclusion. They have a No Bullying policy which is reinforced. We've always said that no matter



what school you go to, the student always has to make it work. Bailey plays her part in making school work for her.

She's a whiz on the tablet and computer, and technology has really helped her communication. She has learned to use Makaton sign and combines this approach with 'Bailey Signs'. She also chatters non-stop – once you get to know her you come to understand she has a lot to say for herself. College awaits, and we'll make a decision at the time as to where Bailey will be enrolled.

There is an economic impact for parenting a whanau member who needs technology to assist with communication, glasses, hospital appointments, and a particular diet related to coeliac. Our employers

have been brilliant in their support with our extra responsibilities connected with parenting Bailey.

What do we want for her? We want all our kids to be fed and looked after, and everything else will be dealt with as we come to it. We can see Bailey working and getting on with the usual day-to-day stuff that the rest of us are involved in. We want her to have friends she has coffee with, money earned through work so she can make choices around lifestyle and independence, and for her to do what makes her happy.

***We want Bailey accepted for who she is. Bailey is Bailey. She is who she is.***



# LOVE STORY ABOUT FAMILY, FAITH AND HOPE

by SUE ROBERTSON

**T**his is a family story about faith, hope and love, and the importance of relationships based on respectful communication and respect for families.

## AIGA AND MAGAFAOA (FAMILY)

I met Brian and Betty at Easter, a significant event in their faith and cultural calendars.

They talked about their aiga and magafaoa, of three sons, and their experiences parenting Roman, their first-born.

His autism affects the whole family and his brothers Joel and Zechariah have been an important part of his journey.

Roman is able to draw on wisdom from his grandmothers and support from the extended families – Brian's

magafaoa are Niuean, and Betty's aiga are Samoan.

He is the reason they started the Pacifica Autism Support Group (PASG). "Our experiences with autism and the journey with our son is why PASG was so important to set up."

## HOPE

Roman is 13; a Year 9 adolescent in his first year at high school. Brian and Betty tested their thinking with each other all the time, as this has been a significant time for them too.

Where would Roman feel welcome? Where would he learn best? As busy full-time working parents, did they have the time and energy to influence the senior education system? It had to flex and accommodate a student who needs extra support and well-informed





ROMAN

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strategies, supported by well-trained teacher aides alongside skilled and accommodating teachers.

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## THEY SEE HIM WORKING IN THE COMPUTER INDUSTRY AS A LEADING TECHNICIAN WHO MOVES THE INDUSTRY FORWARD

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If anyone can support New Zealand to move forward through resourcing learning environments that address

and remove barriers preventing all teens from learning together, then Roman is a leader for his time.

He happens to have the attributes of autism – a young man of few words, although articulate when he chooses to talk about things of great interest to him, like asking dad to support him to buy technical parts for his current project to enhance the console system. With a special interest in technology and how things work, the world as he knows it would end if his iPad disappeared. He also joins in with family sports activities.







Brian and Betty want Roman to thrive and become self-sufficient. They absolutely see him working in the computer industry as a leading technician who moves the industry forward on multiple levels, including paving the way for business and industry to employ people who think differently.

### LOVE AND FAITH

Brian and Betty's story is a love story based on their love for each other, for their sons, for aiga and magafaoa, and expressed through faith.

What keeps them focused and wanting to influence and drive change and make the world a better place for their families and people who connect with them? They believe "Our Faith is our Strength".

***The scripture that encouraged their family after Roman was diagnosed comes from Jeremiah 29:11 "For I know the plans I have for you," declares the Lord, "plans to prosper you and not to harm you, plans to give you hope and a future."***

# The Goals of a Global Messenger

by CLARE CHAPMAN

**P**ortia Johnson, 23, is into music and wants to go to New York to see her favourite musician Taylor Swift. She works part-time as an administrative assistant at a daily newspaper and, like most in her generation, she's got her smart phone close. Having left home for a flat, then returned to the nest, she would like the independence of flatting again.

Portia is just like any other 20-something – but unique in her own way. She was born with a mild form of Cri-du-Chat syndrome, a chromosomal condition characterised by intellectual disability, delayed development and weak muscle tone in infancy. She completed high school in a special needs unit within a mainstream school, and hasn't let disability hold her back.

With a range of achievements and interests, her latest is election into the Special Olympics Global Messenger programme in late 2016. As a Global Messenger Portia travels independently to meetings and has to develop and work on her goals – a personal goal, a sporting goal, and a goal as a Global Messenger.

To become a Global Messenger, Portia first had to be nominated, and then selected from a large group of applicants – she is one of 10 messengers this year. She went to her first workshop as a Global Messenger in Wellington in early 2017. It was a significant step for her travelling alone.

"It was a bit different. There were people meeting me at the airport 'though, and I have flown to Australia myself too, so it was OK," she says.



Portia



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The Global Messenger programme is about educating athletes to gain the skills and confidence to spread the message and vision of the Special Olympics movement. They speak within their community and around New Zealand at seminars and conferences, addressing intellectual disability, Special Olympics and their own experiences.

Swimming is something Portia's been involved in for nearly as long as she can remember. "I think I was about eight when I started lessons and it went from there really." She's modest about her achievements,

and it was only with a bit of prompting from mum Karina that it became clear her swimming coach found a lot of inspiration in Portia.

Teaching Portia to swim, and seeing the different ways children learned, prompted her coach to start a Special Olympics swimming team/school in Te Awamutu, and to this day she remains Portia's coach and mentor.

Portia's goal is to master the art of tumble-turns so she can improve her speed.

"Swimming is good for fitness, and it's good because I know heaps of



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people through swimming and make friends," Portia says. "We sometimes travel for competitions around New Zealand too. I did the nationals in Dunedin and last year I did an international competition against Australia."

Mentioning the international competition, her eyes light up and it's clear this is where one of her passions lies.

"When we go to competitions, and you have people handing out ribbons, it's often a mayor or someone from the government. And I thought, well that's a bit boring. I want to get paralympians to hand out the ribbons – that's one of my goals this year."

Portia's also keen to speak in schools about Special Olympics. "I'd like to get people more aware and more people involved in it," she says.

Public speaking is no new thing for Portia, whose debut was an emotive and well-received speech to her high school in her final year.

"You could hear a pin drop," she says. "I had seen my friends in the special unit bullied and I couldn't be head girl or anything, so I decided to do a speech about it."

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**With a range of achievements and interests, her latest is election into the Special Olympics Global Messenger programme in late 2016.**

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Her 2017 year as a Global Messenger, swimming training and personally, is busy. She swim trains once a week, is involved in Riding for the Disabled, works part-time, and has a host of interests including modelling, which she's had some success with so far.

***She's a 20-something with goals, and is well on the way to achieving them.***

# Getting to know incredible JOY

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by SUE ROBERTSON

**“Joy's name was chosen before she was born and that's what she has been, a joy. She is our third child and we have been lucky to have her in our family – and she has been lucky to have us,” her mum Kathy says.**

"Joy was a very sick baby. Born in Taiwan, she spent her first few weeks in an incubator on 100 percent oxygen. There was a clinical experimental drug available to give her a chance, but this was going to take all our family's savings. So we prayed, and Joy gradually recovered. We brought her home when she was 20 days old.

"A neurologist told us she probably wouldn't ever walk, would probably have eyesight problems, some mental retardation, and wouldn't live much beyond 20 years."

It was the cruellest thing Kathy had ever heard. "I cried so much, and

then I said 'Whatever! I'll just do my best!'

"We knew God loved our baby and we knew our life's work was to make sure Joy was going to have the best life we can give her."

Joy's family moved to New Zealand in 1997 and settled in Hamilton. When Joy wanted a bike just like her brother and sister, she got a tricycle and rode this to her local kindergarten. It was attached to a high school that had an Early Childhood programme run by people who were open-minded and innovative.

"The most challenging obstacle for me was always my identity," Joy says. "Why am I different to normal people, and why I just cannot do some simple things as well as I expect? The idea that thoughts determine your future has always helped me to remain positive."



Joy

Kathy said the family didn't think much about 'special' – they just went with the flow and enrolled Joy at her primary school with her sister. Joy went on to the local intermediate and graduated from high school in 2009.

Her experiences at college were mixed. Although mainstreamed for academic classes, Joy was less involved with her typical peers and

more orientated towards her friends in the unit where she felt socially included, describing them as people who appreciated diversity, who were compassionate and humane and able to 'count on each other'.

She got her first paying job at age 12. One of Joy's strengths is persistence, and Kathy learned to ask: "How do we make this happen?"

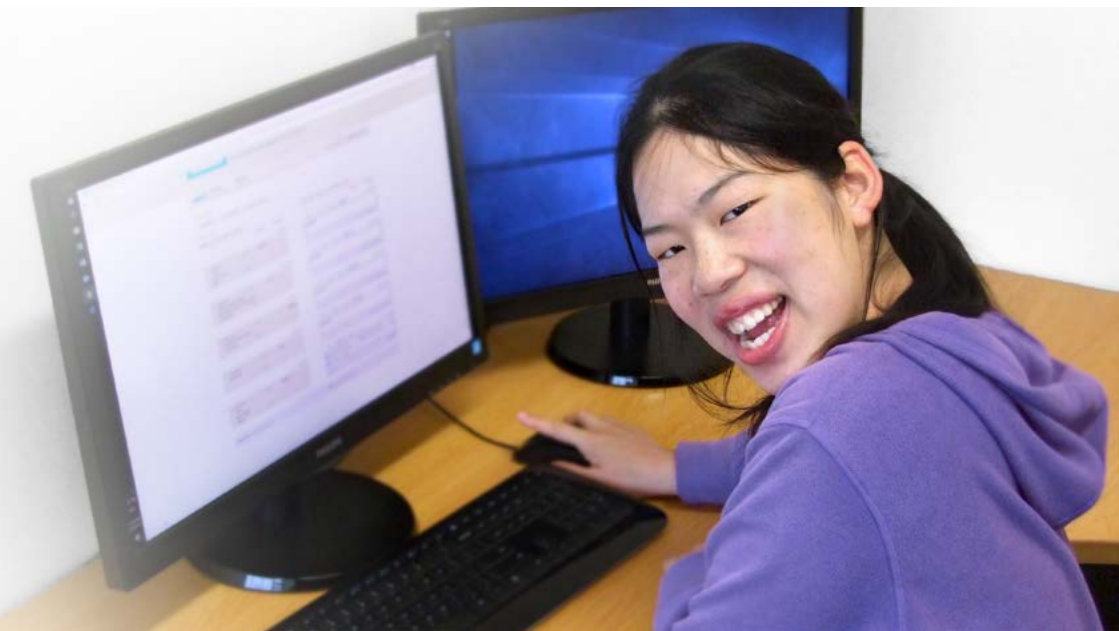
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"I started delivering local newspapers after I saw a friend doing it. I'd heard the waiting list was way too long for me to have any chance of delivering newspapers, but I rang the supervisor anyway and put my name down as a reliever," Joys says.

"The supervisor's name was also Joy, and her voice was so bold I got a fright when she rang up offering a position – my sister took up the offer instead. Rain or shine for the next two years my sister and I delivered 130 local *Hamilton Press* newspapers every week after school – my sister on her bike and me on foot using a back pack with support from mum.

"My sister eventually left home and I took over the job and continued to share the deliveries with another friend, during which time I developed an interest in money and accounting when I began to split the wages. During 2006-2007 I also delivered a second weekly newspaper and some advertisement pamphlets with the same job partner, and this increased my newspaper deliveries to three days a week.

"My trike arrived in 2008, customised to hold 30 kilos. I gave up two deliveries and started to deliver the daily *Waikato Times* (without mum's support). It was a 30-copy six-days-a-week delivery; I





# MESSAGES FROM JOY

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## TO PARENTS & FAMILIES

First, thank you for all your efforts in raising a disabled family member. Your support is the most important factor that will influence their life.

Your belief in them is also vital, but don't cover them too much from the harsh realities of this world. Independency is a critical element that you should gradually teach them if possible. Please give them some freedom to make mistakes, for this is a way for them to grow and gain the ability to explore their endless opportunities. The world is at their feet.

## TO PEOPLE WITH DISABILITIES

Don't give up! Live life to the fullest and shine in your own way.

Each person's life is like a storybook; only you can write your own story.

The thing I like most about New Zealand is the rainbow after the rain, which exactly resembles this quote: 'Everybody wants happiness, nobody wants pain, but you can't have a rainbow without a little rain.'

Just go for your dreams; never give up; you'll be surprised what you can achieve!! The sky is your limit.

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did three days and my job partner did the other three."

Joy delivered papers for more than seven years, becoming the *Waikato Times'* longest paper-run girl and making front page news. She was awarded Youth of the Year for her paper-run role.

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**"I finished a Bachelor in Management Studies majoring in Accounting, after six years of study."**

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"After graduating from college I enrolled at Waikato University. Campus life and study held some challenges. There was a third-year taxation course which required me to carry four books weighing 2kg each to every class, and I was always afraid of tripping over. The action of sticking hundreds of post-it notes within the thousand pages of each book for easy reference when needed was very challenging for my wobbly hands. Still, I finished a Bachelor in Management Studies majoring in Accounting, after six years of study for a four-year degree.

"I had always wanted to return to my home town in Taiwan and after

completing my degree I returned for eight months."

While there, Joy visited one of her early therapists, now a lecturer, and was asked to talk to students about her New Zealand education experiences. Wherever Joy goes her story touches people. A deputy head present in the audience was impressed and offered her a job of research assistant.

"I flew back to New Zealand by myself. Ours is a multigenerational family – I live independently in a unit on the same property as our family home. Thanks to my mum's belief in me, I'm able to do most things myself. I'm close to mum if I need her support, and now I'm an aunty!

"I'm hoping to find a job in New Zealand where I can utilise my limited strength, and gain some relevant experience with my accounting specialisation and management degree.

"I also hope that I will be able to continue to grow in maturity, meet great mentors, and make life-long friends who will not make my journey so lonely."

***Joy is a strong, resilient, persistent woman. Her family say she has been blessed by God.***



# Parent to Parent

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**Parent to Parent can connect, inform and support you and your whānau through the day-to-day realities of caring for a child with a disability.**

We provide three main services to families raising children with disabilities. Our services are free and confidential.

- 1 We connect new families with specially-trained volunteer support parents who have a family member with the same or similar disability to your child.
- 2 Our dedicated research team provides free information on any subject related to nearly 4,000 conditions from the rare to the common.
- 3 Living with a brother or sister who has a disability can be challenging. We run programmes to help siblings thrive in their unique family environment.

We also offer a range of programmes, workshops, events, as well as a quarterly magazine. See our website for more details.



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**ImagineBetter offers information, advice, planning support, mentoring and events for disabled people, families and organisations.**

Imagine Better's practice is based on principles and research-based evidence. Together with local and international thought leaders, it hosts events to challenge and change how people think about disability.

ImagineBetter offers Local Area Coordination (LAC) in the Western and Eastern Bay of Plenty, and the Lakes District. LACs work with you and your whānau to help you imagine what a good life would be for you. They then connect you with local people and resources that can help you make your ideas a reality.

LACs also support communities to be inclusive and accessible to people from all walks of life. They work closely with local people, businesses, organisations and marae.

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