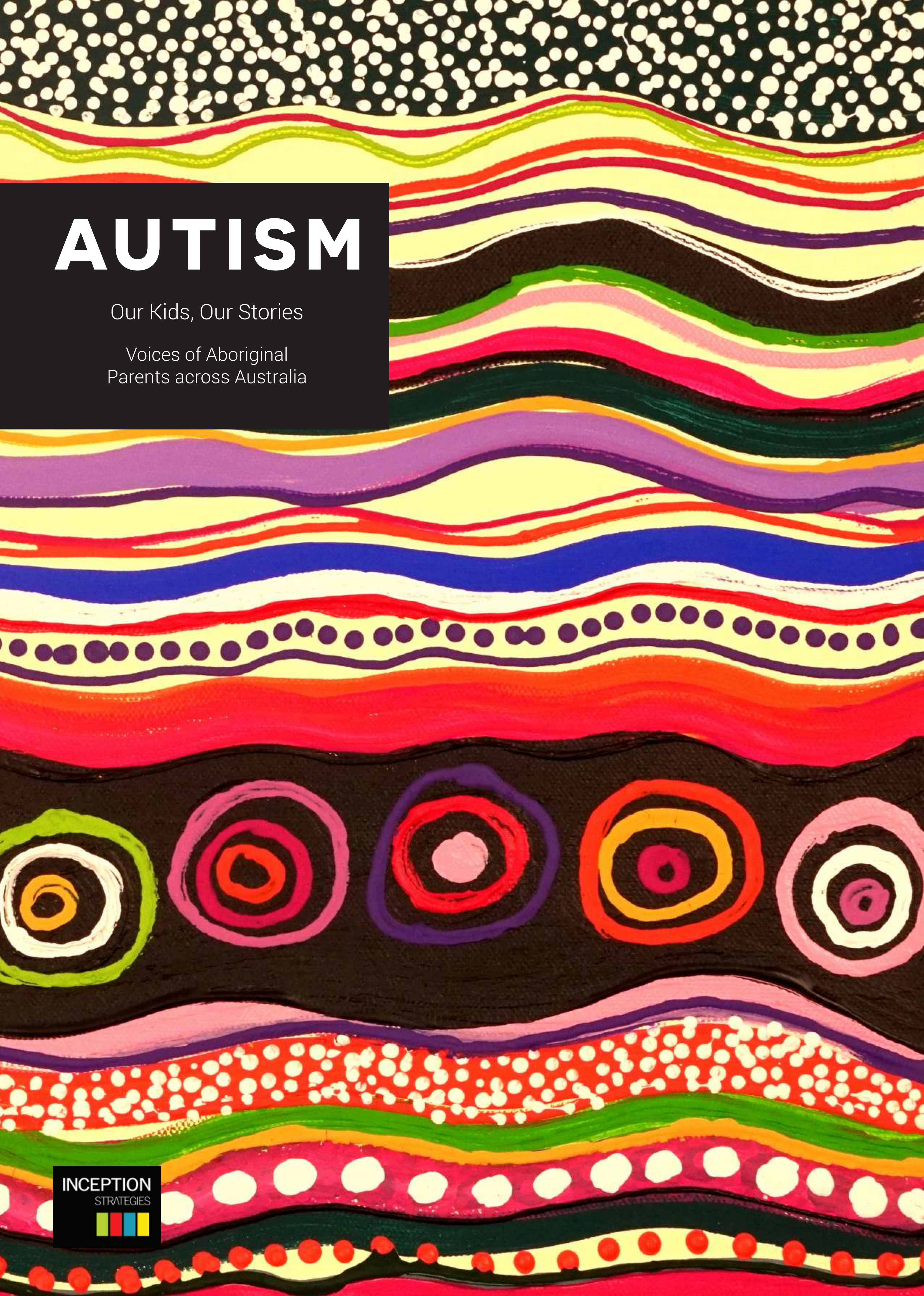


AUTISM

Our Kids, Our Stories

Voices of Aboriginal
Parents across Australia

INCEPTION
STRATEGIES

Acknowledgement

Positive Partnerships is deeply committed to working positively and in culturally sensitive and meaningful ways with Aboriginal and Torres Strait Islander peoples to talk about children and young people. We acknowledge the struggles, strengths and contributions of Aboriginal and Torres Strait Islander peoples.

We pay respect to cultural ways and peoples' connectedness to lands and sea.
We pay respect to the cultural value of storytelling to make and give meaning.
We pay respect to elders, past, present and to our little ones, the future leaders.

pp positive partnerships
Working together to support school-aged students on the autism spectrum

Positive Partnerships is a national project, funded by the Australian Government Department of Education and Training through the Helping Children with Autism package. We are delivered by Autism Spectrum Australia (Aspect), with a goal to improve the educational outcomes of school-aged students on the autism spectrum. We work with schools, communities and families across Australia to deliver evidence-based content through workshops, webinars and online learning through our website. This initiative is funded by the Australian Government Department of Education and Training through the Helping Children with Autism package. The views expressed within this publication do not necessarily represent the views of the Australian Government or the Australian Government Department of Education and Training.

"A Spectrum of Colours"

Painted by : **Maria Watson-Trudgett**
Language Group: Wiradjuri

My vision for this artwork was to highlight the diversity of autism by using many colours and movement in my painting.

- All colours, dots and wavy lines represent the diverse spectrum of autism.
- Black band represents Aboriginal communities.
- Coloured circles represents Aboriginal family units and their individual family journeys with a child on the spectrum.

Foreword

By any measure, Aboriginal and Torres Strait Islander people with disability are amongst some of the most disadvantaged Australians. Addressing the unmet needs of Aboriginal and Torres Strait Islander people with disability is one of the most critical social justice issues in Australia today. Moreover, it's estimated that 50% of our population has some form of disability or long-term health condition.

Currently, most Aboriginal and Torres Strait Islander people with disability remain at the periphery of the care system that is designed to serve them. One factor that remains little understood, is the reluctance of the Aboriginal and Torres Strait Islander people with a disability to identify as being disabled. For example historically, in Aboriginal traditional language there wasn't a comparable word for disability. This suggests that disability was an accepted part of the human experience.

> "Due to our history, many Aboriginal parents can be reluctant to identify their children as having a disability because they worry that this could be seen as them not being able to adequately care for their children and as a consequence worry about their children being removed."

> "In the words of our organisation's founding Elder and Statesman (Vale) Uncle Lester Bostor AM.
>
> My whole life has been reacting to needs. That is what it was all about, helping other people and creating change.

We at First Peoples Disability Network argue passionately for positive change to happen in the lives of our people with disability, that it must be driven by the community itself. However, it is the resources to support our people with disability that many communities lack.

This book, developed by Positive Partnerships, can support our parents and carers to identify children who may need assistance. Aboriginal and Torres Strait Islander people are traditionally an oral and visual community. It is the cultural way of telling and sharing stories with our mobs, that is the natural way to learn and educate.

For many children in our communities who are not formally identified as having difficulties in areas such as learning or behaviour, concerns are often only raised when they reach more structured environments such as school. Having a resource available like the 'Voices' storybook will support families to both understand these concerns and provide a connection to other parents in a similar situation.

> “The value of having a resource, that shares the lives of our families through their personal stories, can open doors for many to not feel shamed and understand that support is available.”

“Voices“ is giving strength and education about autism to our mothers and kinship groups. These stories, can change the life trajectory for many of our Aboriginal and Torres Strait Islander children nationally, in a positive and culturally appropriate way.

First Peoples Disability Network would like to thank Positive Partnerships for their passionate and respectful work in our Aboriginal and Torres Strait Islander communities. The development of this book of stories, with families yarning from their lived experiences, is acknowledging our cultural way to engage. Your vision to create change and educate families living with autism in our Aboriginal and Torres Strait Islander communities is truly valued.

Thank you

June Riemer

Deputy CEO
First Peoples Disability Network Australia

Contents

Anita

I’m married to my husband Ben Snr and have six children; Leila, Thomas, Gabby, Donald and Benjamin. We first noticed something was different with Donald and Benny when they were babies. They seemed very quiet, observant and preferred to do things in routines and patterns. They both had difficulty reading body language and did not pick up on the normal cues. There was a real seriousness about their manner, as they were trying to pick up on what was going on around them.

When he was older, Donald would often get three cups of water for himself and his brother and sister. Years later when his brother and sister went to school and there was only him home, he would still go and get three cups! Donald prefers things with wheels and has been riding bikes from a really early age and he has no radar for speed or danger, which worries me sometimes as a mother.

We are teaching Donald how to use his fingers to do mathematics and times tables. Once he starts his times tables he prefers to go all the way through to the end and it’s been a challenge to help him stop at a certain number to solve the problem.

Donald is starting to appreciate the ‘in between’ parts of life while Ben still sees everything as black and white. If we announce that we are going to the pool, Donald has a time horizon to understand the idea of ‘later’ whilst for Ben ‘later’ simply does not exist so it must be ‘now’! Ben also has a particular way of walking into and out of my father’s house. If for some reason he is distracted and doesn’t leave in the ‘correct’ way, he thinks nothing of walking back inside the house just for the sake of walking out ‘properly’.

Now Donald is eight years and Ben is six years, we decided to take the path of treating them the same as their siblings. Consequently, neither one is very ‘aware’ of their autism. Notwithstanding, both are very empathetic towards other children with learning difficulties and often help them at school.

> “ I don’t see autism as a disability just as a way to learn and process things differently. ”

The boys have a very high level of sensitivity for people and environments around them. We are a Catholic family and have had a regular connection with Nuns from Mother Teresa.

One day, some years back, I was on the phone at home and Donald came and pulled my hand to say that ‘someone was here’. I ignored him for a minute whilst he dashed down the hallway towards his bedroom. I then hung up the phone and watched Donald emerge holding something small in his hand. When I took a close look, it turned out to be a rosary and when I asked him where he got it from he just said the “Lady in my room”. I went down there and saw his room was empty so it’s something the family has not been able to fully explain. But Donald has held onto the rosary for all of these years and still has it today at the age of eight.

Looking back, the first five years with the boys was tough in terms of them not speaking much at all. It’s something that’s so easy to take for granted, but when it’s missing and you are having difficulties communicating with your children, even tiny leaps forward can feel like mountains have moved.

Most of the time, I need to prompt the boys by verbally explaining their choices. Ben startled us recently because he showed independent thinking for the first time. I had asked him “Ben what’s your favourite food? Sausages or steak? And to our amazement he replied,

> “ Mum, I like sausages and steak, but I really like chops! ”

Billie & Cliff

Our daughter Emily is 12 years old and has been diagnosed with autism. Emily has a mixed but proud heritage stemming from her father Cliffy, who is an Aboriginal man from the Yuin people and my own English/European descent.

> “Cliffy and I quickly realised that Emily was different to other children as she had some speech problems, social integration issues and did not want to be left alone or away from us for any period of time.”

There were other issues too and we sometimes felt that Emily should have taken more responsibility for her own actions and we felt exasperated and exhausted when she refused to.

We later received a diagnosis to help explain why Emily had some of these issues, which made us feel guilty for blaming her when there was a medical reason preventing Emily from taking responsibility. Dealing with this guilt has not been easy for us as Emily's parents.

> “Cliffy launched into his culture, attending men's groups and participating in Aboriginal art and painting, which has been positive.”

> Once we received Emily's autism diagnosis, we both felt a huge sense of relief because it gave us answers for the speech and social issues Emily was experiencing. The diagnosis opened up new opportunities for us to get real support, including speech pathology and special education.”

Emily's school has worked with us to develop a learning program for Emily that takes advantage of the way she learns best. Likewise, our speech therapist works closely with Emily and has made good inroads over the years to help with her speech.

> “Our hope for Emily in the future is that she learns to communicate, make friends and be able to socialise.”

We are also teaching her to be more independent with toileting and hope she can do this on her own one day.

> “We are our daughter's best advocate.”

Dr Samarra

My traditional name is Jilangara Gulbari and our son, Artere-Desmond, has Aboriginal/Ganagulu heritage from me and Maori from his Dad. In his early years he hardly spoke at all and struggled to engage in social interactions with children his age and other family members. The slightest change to the schedule, foods or even the home routine would trigger distress and leave us powerless as he suffered through emotional meltdowns.

He was also hypersensitive to noise, textures and the feeling of certain materials, objects, food, play items, smells and lights. Exposure to these things often led to severe distress. At some point all we could do was cry, but we remember that tomorrow is always a new day and, for the most part, our days are filled with laughter.

> “Overwhelmingly, despite the pain of seeing him struggle to tell his Mum and Dad what he needed. An autism diagnosis at the age of 4 meant we finally had an answer and we started a journey that has changed all of our lives for the better.”

We moved all over the state to get him into programs. We spent hours on the phone seeking the best services, finding institutions that support our vision for our child - not what the world dictates we should do.

We scheduled our family activities around his therapy and school and created autism-friendly events he could safely attend. We created learning and social opportunities for him every day that he could participate in, by communicating with centres in advance to help them understand his autism and create a safe sensory space for him.

> “We spent time creating healthy organic meals to nourish his body. We developed physical activity sessions and therapy sessions in our home, using equipment and programs tailored to help children with autism that I have designed with a clinical focus.”

I withdrew from full time clinical work and became a part time doctor - my son became my focus and we had one parent with him always. Now I find ways for our son to enjoy activities such as art (which he previously struggled with because he disliked the texture of paints), and he now creates the most amazing artworks.

> “As his parents we are best placed to lead the ship and navigate the sea of autism.”

We have accessed a number of schooling models: early intervention, public and private schooling, part time and full time schooling and more recently distance education - which has been superb.

Improved Connection to Culture

> “Our community includes our son in everything and he learns traditional dance, stories from our Elders and soon we will begin teaching him language. Our son visits our special places and learns about his traditional country.”

Autism has made our connection to country and culture stronger. We have created many resources for our son and have adopted many strategies that focus on communication, socialisation, sensory processing, self-regulation, speech, and increasing his body strength and motor skills.

We have created and will continue to foster a community to love and support him long after we have passed.

> “We choose to celebrate our son’s success - what may seem small to other families can be truly momentous for us. Our son will become what he wishes. We only dream of a healthy and happy life for him.”

> “Who knows? Maybe a child with autism could one day become your boss, or the woman who invents a medical device that will save your life, a surgeon who is obsessed with precision and detail who operates on you, the artist who creates truly beautiful work that millions may love, the mathematician who solves equations that change science, or the tech guru who creates that next smartphone for your hip pocket.”

Jacinta

I'm Jacinta Ladgrove, a proud mother of three gorgeous children and wife of my wonderful husband David. I'm of Yorta Yorta descent on my grandfather's side and Gunai Kurnai descent on my grandmother's side and we live in the Greater Shepparton area in Victoria.

Before getting help, my youngest son, Nathan, was mostly non-verbal, wouldn't interact with other children, would only eat certain types of food and had issues with sleeping and toileting. We lobbied for Nathan to repeat kindy as we had a feeling deep down that our son was not ready to start school, but he was later assessed by the Education Department who told us that Nathan should be enrolled in a mainstream school. Luckily, a small rural school accepted Nathan's enrolment, but before the first day had finished, the school was on the phone to my husband suggesting that Nathan had something called AUTISM? After quickly researching it, I was in shock.

> “My emotions ran something like, “No way did my son have this condition, the school didn't know what they were talking about!”

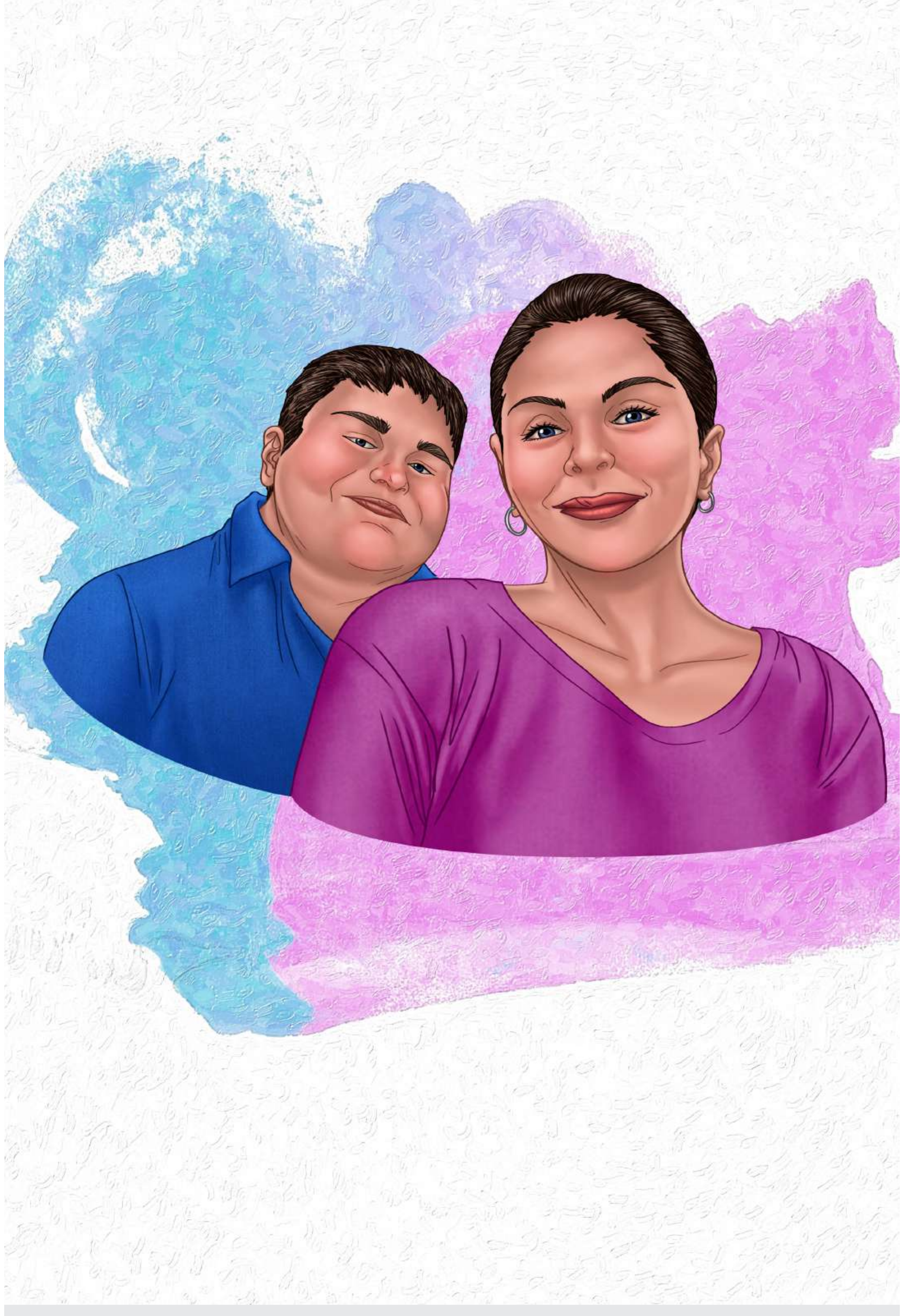
Nathan was medically diagnosed with autism a few weeks later. The diagnosis took a while to sink in and sometimes the grief just felt overwhelming.

As we learnt more about autism behaviours, alarm bells started ringing in our ears as our eldest son Mathew had also been out of school since the age of 12, due to behaviours that were also on the 'spectrum' for autism. He had issues with socialisation, toileting and sleeping, refusal to eat in front of others and would only eat specific food types. At home, Mathew was a perfect child, but put him in the school environment and he just couldn't cope.

I had to reduce my hours at work to accommodate for all Nathan's assessment and therapists appointments. Sometimes I felt like a single mother as I had to take Nathan to all of his appointments on my own as my husband was 'in denial' about Nathan's autism diagnosis.

I later founded an Indigenous Autism Support Group for our community. It's been over four years now and we are still meeting on a monthly basis with thirty-three families registered.

> “Following all the support and therapy we received for Nathan, you can now actually have a conversation with him, but he still gets jumbled at times, if he gets excited.”



Nathan is attending a special school in the Middle Years (6) and will be turning thirteen in August. He still struggles with change, so I remind Nathan daily about what's coming up, because if something pops up out of the blue, he is just not going to cope.

> “Nathan has a big heart and is a literal thinker. When he asks questions, I have to be so careful in how I answer him, as he believes nearly anything I say. For example, if I say it's 'raining cats and dogs', Nathan would be looking out the window waiting for cats and dogs to fall from the sky.
>
> I've signed Nathan up for boxing this year and he absolutely loves it. I'm lucky to have support from my local community, workplace and family. The saying 'It takes a village to raise a child' is true and I'm lucky I have an awesome village.”

Thank you for allowing me to be a part of this amazing book. By sharing my story I hope that other families will have the courage to speak up and ask for help.

Lena

My name is Lena, I'm a Yorta Yorta and Gunaikurnai woman, a mother and I have twelve grandchildren and two great grandchildren.

In the early days, two of my grandkids seemed happy enough but they were unable to talk, so communication with them was challenging. As they grew, I noticed changes in their behaviour. For example, they started developing a fascination for door handles, swings or even my hand and would spend time being very close to these objects to appreciate them. They sometimes also liked to walk around on their toes whilst making unusual facial expressions.

> “Both grandchildren were also very particular about arranging their toys in a clear order that was important to them. Going through this, I was feeling for my daughter's suffering in managing her kids, and my main concern was how to best support them.”

Both children were eventually diagnosed with autism, but they each display different behaviours from each other. For example, one needs medication to sleep properly and the timing of sleep is really important. If he falls asleep in the afternoon outside of his normal schedule, it can cause him to become disorientated, throw out his body clock and lead to long-term meltdowns. But the other one doesn't have to have his sleep controlled in the same way.

Our family also worries about the children at school as they have experienced bullying from other kids. There have even been times where one of my grandchildren had their pants pulled down. This caused great distress and meltdowns in the afternoon after they got home.

While these events might seem like innocent play to some people, they upset the harmony in our family for prolonged periods. Harmony, that is sometimes very difficult to win and so it's much prized. This is why it's so important that teachers and school principals listen to and engage with us, to support our kids.

My daughter has taught the kids to get the bus to and from school and now the kids love the bus. She has also taught them about table manners and so when the children come to my house, I follow the same rules.

> “The children are not viewed as different in our family, we accept each other and are proud of who we are. Our family is very big and at Christmas over thirty of us”

We have great grandmothers, great great grandmothers and great great grandfathers who join together with us and the children.

> “My hope for the future is that there are better respite services available for parents and growing support for our children in schools.”

Melanie

My name is Melanie Mununggurr-Williams of the Djapu people of North East Arnhem Land. I'm a proud wife to my husband, Burger, and mother to our six year old extraordinary son Molyun Xavier. From the very first time I held him in my arms,

> "I knew Molyun was special. He is so much of what is good in the world; kind, funny, imaginative, empathetic, active and loving with a warm heart and bright intelligence."

Molyun was two years old when I began to notice behaviours that didn't seem right. He appeared to have no fear and was not afraid to take risks that might severely hurt him and his pain threshold seemed very high. We also discovered that Molyun's senses were quite often completely overloaded. For example, Molyun would have extreme discomfort being wet, with just one drop of water feeling like overload.

Molyun's speech also became a cause for concern. He would give lengthy monologues that didn't sound like he was speaking in English and would become frustrated that he was not being understood. It became apparent to us that Molyun had a speech delay and trouble forming his words. Taking matters into his own hands,

> "Molyun made up a language of his own, which was looked upon adoringly by many people especially our family of fluent Yolngu Matha speakers."

As Molyun grew older, his speech delay and sensory issues became more evident.

We researched and spent hours on the internet listing all of the behaviours I believed to be unusual for his age. All the while I was dodging judgemental stares and comments from community members on a daily basis, as I tried to get through each hour of the day without a Molyun meltdown.

Molyun was diagnosed with autism at a level 2 severity not long after his 4th birthday.

> "The relief was unexpected and although it gave us a starting point, I also understood the enormity of having a child with autism could not be ignored. It was time to strap in and hold on for the ride of a lifetime."

Molyun's arrival on this earth has made the world a better place, and me a better person.

There is not a day that goes by that I am not grateful for him. Autism and Molyun are one. There is no separating them, but autism does not define my son, who he is and what he will become.

> "For regardless of how rocky the road might get, all it takes to move forward is to place one foot in front of the other and take one step at a time."

Sheila

My name is Sheila and my son Shemar-ray is seven years old. My language group and people are the Nyangumarta people of the Pilbara in WA.

I noticed early on that Shemar-ray was developing differently to my first born son. Shemar-ray played 'in his own way' with cars and trucks and repeated exactly the same patterns and movements. Shemar-ray seemed to suffer pain if his line of cars or his collection of small toys were moved or disturbed by others. When Shemar-ray was 3 years old, I came across an article about 'autism spectrum' and I quickly saw that Shemar-ray was exhibiting some of the same characteristics and behaviours.

My thinking was confirmed when Shemar-ray was diagnosed with autism at 4 years old.

> “At least his diagnosis gave me a way to describe my son's special ways and behaviours to my family.”

Shemar-ray loves to sing and he has a beautiful singing voice.

> “I talk to family about Shemar-ray being different and still need to explain that he is not being naughty if it seems he is not listening. I say, “his ears can hear, but sometimes they are tuned in to other things.”

Shemar-ray's grandfather is a linguist and Shemar-ray understands four languages including some English, yet it's hard for him to speak.

> “He understands Mudbudda, spoken in and around Elliott NT, Nyangumarta in the Pilbara WA, (spoken by me and my father) and Walmajarri, which is spoken by my mother from the Kimberley region in WA.”

Initiation for Shemar-ray will be a time of thinking and working through what we can do, what is expected and what is best for him and his connection to culture. Shemar-ray will need a lot of time and assistance to understand this.

> “I hope Shemar-ray grows strong and that getting his words out becomes easier for him, leading to more independence. I hope that Shemar-ray has dreams about his own life.”

Steven

I'm a Kamilaroi man who grew up in Tharawal country. I live with my wife Sara, son Anderson and daughter Penelope. I'm also acting assistant principal at Camden South Public School.

We first noticed my son Anderson was different when he was about 18 months. He seemed to be avoiding making eye contact with us and he didn't respond at all to people's voices. We first thought he was deaf and Anderson soon received treatments and grommets for a middle-ear infection.

At 2 years, we took him to see a paediatrician who said that we had 'nothing to worry about.' But when at the age of 3, Anderson still couldn't speak or express himself we took him for another assessment. This time, the doctor diagnosed him with autism plus an intellectual disability. It felt a little like a kick in the guts. My wife and I didn't really talk about it for a while as we were both struggling to deal with it internally. On the positive side, my wife and I eventually realised that closing off from each other wasn't making things easier

> “so we developed a new language of forgiveness, permission and gave up on ideas of 'perfection' that had previously limited our thinking.”

This strengthened us as a couple.

Anderson started therapy at three and a half years and responded well to Occupational Therapy. Getting him into see specialists wasn't hard, but finding day-care providers that understood special needs children was almost impossible. One of the best things my wife and I did was a 12 week program of therapy which taught us as parents how to work with Anderson instead of trying to get him to work to us.

We knew that Anderson couldn't attend a mainstream school. We eventually got him into a privately funded school which is targeted for children on the spectrum. In the longer term, we are hoping that he will transfer to a local school which has a Tharawal name for meeting place.

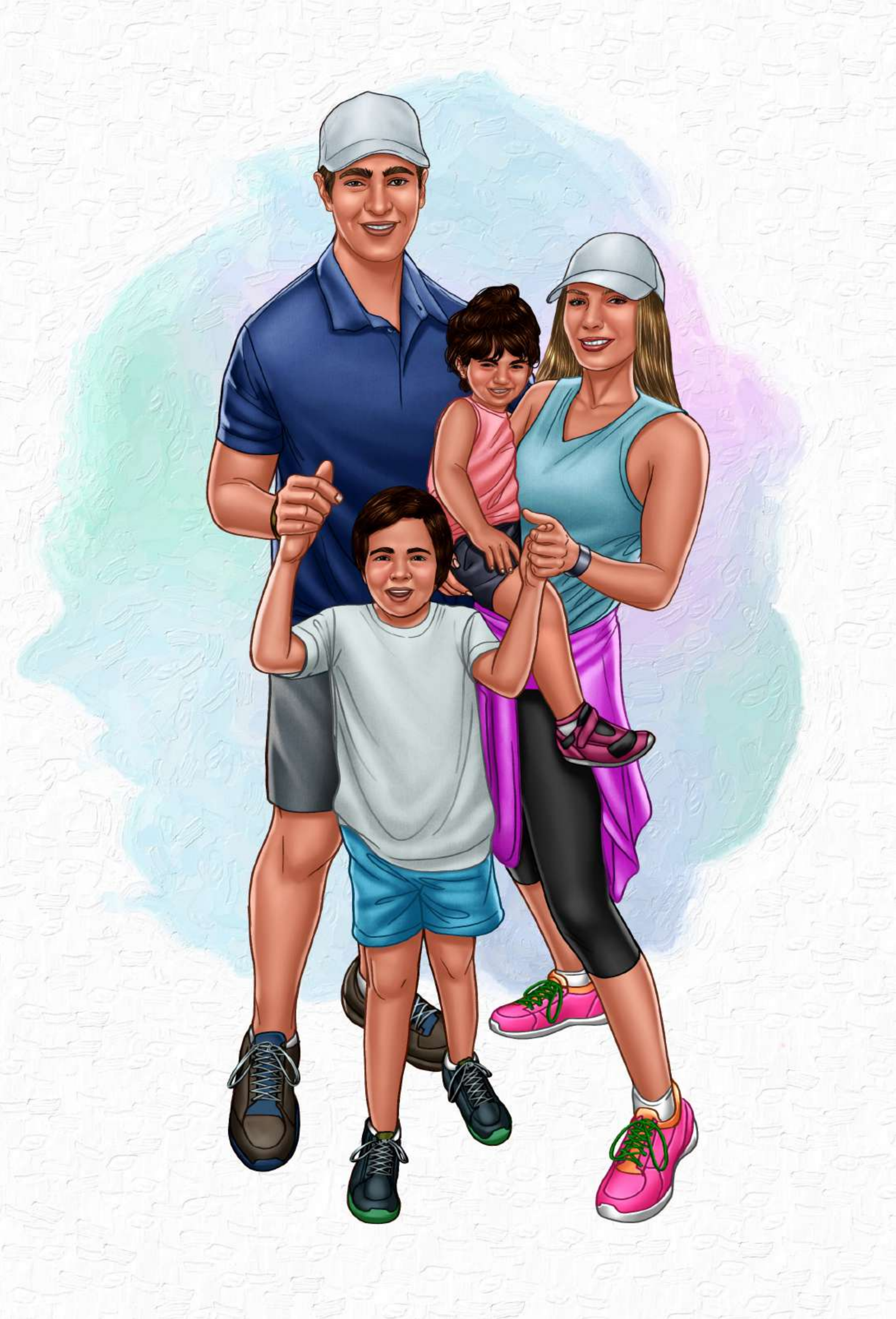
Anderson tends to enjoy smaller group environments with less people in the class. He needs a lot of sensory work that increases his state of engagement and he loves music and movement. If we go into a new place or environment Anderson has to bend down and touch the surface to acclimatise.

> “Anderson loves the water, but hates the sand and likes swimming in pools and lakes. He's no fan of bushwalking, but lately he is drawn to looking at art and the finer qualities of a painting or picture.”

For many years he was indifferent to his sister, however, he is gradually turning around and starting to take more notice of her. Penelope's also developing a better understanding of what is really going on inside Anderson and is showing more empathy towards him.

> “The saying 'if you've met one child with autism - you've met one child with autism' is true, Anderson is a mixed bag. He is also a sweet and gentle soul. We feel that we can learn a lot from his nature.”

We would like Anderson to gradually achieve some milestones that increase his independence. We hope for this, but we plan on this not being the case, he may be with us indefinitely and that's ok too.



Virginia

I'm a Wiradjurj, Kamilaroi and Maori woman. I have five children altogether and my two youngest, Dylan 14 and Miresha 6, are living with myself and their father Steven.

We noticed Miresha was different because she was very non-verbal. By the time she was 3 years and still not talking, we decided to get an appointment with a Paediatrician. He informed us that Miresha had autism. It was a bit of a shock and a lot to take in. Steven took it pretty hard.

I researched as much as I could, and we later met a woman specialist in early intervention who made a big difference by showing me how to connect with Miresha. The specialist gave us the skills to reach Miresha in her world.

Prior to this, one of Miresha's favourite things to do was spin around and around. It didn't seem to make her dizzy at all and she could easily spin for 10 minutes. But once I started connecting with Miresha in a more personal way, she didn't feel the need to spin and the habit died away.

> “Now that I felt more connected with Miresha, I started to look at things differently and even reflected on my own childhood.”

Miresha attends Yr 1 at a public mainstream school. She has a worker with her from 9am-1pm and then for the last 2 hours the Aboriginal Education Officer works with her. School has been excellent for Miresha and she has learnt how to read books on her own. She's got a lot of words in her head - she just doesn't know how to get them out. Miresha's mostly a loner and prefers her own company during recess and lunch-time, but the other kids at school are very sweet and warm towards her.

> “Miresha loves cartoons and is amazing with her drawing. When she sees something once she can draw it and I've been told she has a photographic memory.”

There's a cartoon called ‘Hey Duggie’ on TV with a dog who only says “woof” and doesn't speak, and she loves it. When I asked her the other day, “Miresha do you like the show Hey Duggie?” She said, “woof” which I thought was hilarious from my daughter who is mostly non-verbal.

Miresha loves to play outside on the swing and loves to climb and doesn't seem to have any fear.

> “She also loves travelling in the car and likes to sit in the middle, in her seat so she can see out the front windscreen and let us know when she feels we are heading in the wrong direction.”

Miresha's father Steven often plays the guitar to her and sometimes she will sing along in her own way. They connect through music. Miresha loves to bake cookies and playing with the dough. Miresha also likes cake and her favourite is chocolate.

Sometimes caring for Miresha makes me feel physically, emotionally and mentally worn out. That's when I do some art or craft to express myself to recover. That's what gives me my energy back so I can resume being a mum and caring for her. We took Miresha to the public pool the other day. When we came home I was giving her a shower to clean up and then she looked me right in the eye and kissed and hugged me, which was very unexpected and something she has never done before. Being a parent and a carer can bring some nice surprises.

Natalie

Natalie Fitz, Kathy Fitz (Aunty), Marie Murphy (grandmother), Dan Duggie (grandfather), Army Hicks (cousin), Trent Fitz-Morrison, Michelle Bates (carer)

My son, Trent Fitz-Morrison, has Warlpiri/Warumungu heritage from me and Warlmanpa/Warumungu from his father. In the early days, we noticed Trent had challenges with speech. For a long time he didn't speak much at all, and then later, when the words came closer to the surface, they tended to edge out of him as sounds.

> “Rather than isolating himself, Trent invented his own language using hand signs and then gradually began to teach the rest of the family how to understand him.”

One day he took me over to the kitchen sink when he was only 3 years old, and started making hand movements to mimic me washing his milk bottle. He even mouthed the sloshing sounds that the dishwater makes inside his bottle to show me that it was time for his next feed.

Trent would play a lot by himself, with his cars and trucks, enjoying his own company and would happily fall asleep in the shade of the tree in the yard. When he woke up, if even just one of his cars was missing, he would notice it instantly. Trent was also very sensitive to the placement of things in his room and would notice if even the slightest thing had been moved.

On Trent's first day of kindy, the teacher and the kids were singing the alphabet song. Trent was able to follow the melody but not the words. That afternoon the same alphabet song appeared on television at home. Trent called out to me and said, “Mum, I know this song, MMMMMMM, MMMMMMM..” After Trent's father and I separated, Trent seemed to make the best of the opportunities. His father liked to buy him all the latest battery powered gadgets from the store and when Trent came back home to me, he would raid my cupboards for the batteries to run them. In remote communities like ours, children can slip through the cracks because their special needs are not always identified. Trent was no exception. Somehow, he got all the way to 10 years old before he even had a psychology assessment, which is incredible since nearly every day I was being called in to school because he had gone up to his safe place (on the roof) again.

We haven't yet had an autism diagnosis because we rarely get clinical psychologists visiting Tennant Creek but the specialists Trent has seen have said that he has diverse learning needs.

Trent is a leader and has lots of friends. He is an ideas man and street smart. Trent says he wants to have a family, a car and a job. I want Trent to have a good education, tailored for his needs so he can find himself through his skin name and his identity. Trent is serious about his culture and understands his responsibility for the ‘Water Dreaming’ stories that are handed down to him from his father's side.

Trent is edging closer to the age of initiation. Last year, he and his cousin Jonas had to go to the men's initiation camp and let them know to come home because the women were ready to perform their ceremony dance welcoming the men back into the community. Trent is also a great hunter and knows the difference between fresh goanna tracks and old ones.

> “One day he went out hunting with his Grandfather Dan Duggie and they came home with eight goannas!”

I'm proud of Trent, who he is and where he is going with his life. Over the coming years, I look forward to witnessing him grow into manhood.

Glossary

Psychologist : Psychologists are sometimes called 'psychs'. Psychologists help people when they have trouble with thinking, learning new skills and behaving. They can help people when their emotions are hard to manage. Sometimes psychologists work with people in groups and sometimes they will talk to people by themselves. They often help parents learn new ways to teach their child about behaving and playing.

Early intervention : Early intervention means doing things as early as possible to work on your child's developmental, health and support needs.

Hypersensitive : Hypersensitive means that a person is oversensitive to sensory information. The opposite of this term is hyposensitive, which means that a person is undersensitive to sensory information.

Level 2 severity : When someone receives a diagnosis of autism they are also given a severity level (level 1 to 3) for each of the two domains. Level 3 is more severe than level 1.

Occupational therapy : Occupational therapy can help your child cope with or understand the environment. An Occupational Therapist (OT) is the specialist you would see for occupational therapy. An OT can help with things like toilet training, sleeping, getting dressed and playing with others. OTs can also help with teaching big and small movements, such as writing, cutting, climbing and jumping.

Paediatrician : A Paediatrician is a medical doctor who specialises in the medical care of infants, children and teenagers.

Speech Pathologist/Therapist : Speech pathologists are sometimes called 'speechies'. They can help people to communicate. They can find out if a child is learning how to talk at the same rate as other children. Speech pathologists can help if there are problems with speech sounds/ words or the way they talk to different people. Sometimes they can help with reading.

For more information and resources related to individuals on the spectrum, go to the Positive Partnerships website:

www.positivepartnerships.com.au

FACT SHEET

What is Autism?

What is Autism?

- Autism is also known as Autism Spectrum Disorder.
- Autism is a developmental disorder that occurs in both boys and girls across all cultures and communities.
- Autism affects how a person learns and how they interact with others and their surroundings.
- All people on the autism spectrum are unique.

What are some of the characteristics of autism?

People on the autism spectrum often have problems with communication skills, social situations, behaviour, coping with their environment and learning.

- **Communicating** : People on the autism spectrum may have problems understanding others, talking about their own feelings, following instructions, or maintaining a conversation.
- **Socialising** : People on the autism spectrum may like to play alone or may have problems making and keeping friends. They may not know how to join in a game or activity with others so they find social situations difficult.
- **Behaving** : People on the autism spectrum may have problems behaving appropriately in certain situations and environments. They may dislike change, have a strong interest in one topic or repeat actions or movements over and over again.
- **Coping with the environment** : People on the autism spectrum may have problems coping with noise, touch, certain smells, certain tastes, movement or people and objects around them.
- **Learning** : People on the autism spectrum may find learning difficult at times due to problems with attention and concentration, planning and organisation, understanding what is expected and staying motivated.

People on the autism spectrum have strengths and skills too so with regular, consistent support, progress can be made.

What can you do if you are worried about your child?

Children do develop at different times and rates. If you are concerned about your child's development see your doctor or child health nurse. It is better to have any concern checked than to '**wait and see**'.

Visit the Positive Partnerships website for more information
www.positivepartnerships.com.au

The Positive Partnerships initiative is funded by the Australian Government Department of Education and Training through the Helping Children with Autism Package. The views expressed in this publication do not necessarily represent the views of the Australian Government or the Australian Government Department of Education and Training.