

Dreaming Big, Standing Strong.

QUEENSLAND STORIES OF INCLUSIVE EDUCATION



Expanding Ideas; Creating Change

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Expanding Ideas; Creating Change

Community Resource Unit Ltd
ABN 16 143 460 250 ACN 617 860 009

Level 2, 43 Peel Street, PO Box 3722, South Brisbane QLD 4101

Telephone: 07 3844 2211 Fax: 07 3844 3400

Email: cru@cru.org.au Website: www.cru.org.au





“OUR DAUGHTER IS KNOWN AND SHE KNOWS HER COMMUNITY. ISN'T THAT WHAT WE ALL WANT IN OUR LIVES, TO KNOW OTHER PEOPLE AND BE KNOWN?”

Meredith Irish

INTRODUCTION

CRU exists to create and promote positive change so that people with disabilities can belong to and contribute to community life. The inclusion of children with disability in Queensland schools has never been easy. I have observed and engaged with this question since the late 1980s and it is a topic that has and can cause heartache and division. CRU invests in this work because we believe that inclusive education provides a strong foundation for lifelong inclusion and belonging and we know that change and systems transformation takes time and commitment. As difficult as it is, we need to start to address this issue to maximize the chances of children with disability being able to use their school years as a launch pad into adult life, in the way that most school kids do. As you know, we learn so much more at school than what is on the curriculum. We need to be teaching all children, with and without disability, that they belong together. CRU is not an advocacy organization and we are not laying out a blueprint for change, although we do engage in collaborative efforts to identify system improvements. In our work to build a world where people with disability are included and valued, we believe that continuing to separate children and investing in segregation is not the best way to work towards this.

CRU has collected these stories as part of our Families for Inclusive Education Project funded by the Queensland Department of Education to support families to be clear, informed, confident, and connected so that they can work as respected and valued partners in their children's education. Without this partnership, CRU could not have engaged with such a large number of families across the State or invested in the development of so many family friendly resources. We acknowledge the value of our partnership with the Department and their commitment to resourcing families. We look forward to continuing this work in the coming year.

This collection of stories is an attempt to gather experience and knowledge from a group of Queenslanders who have a personal stake in inclusive education. The stories contain practical tips and strategies, but are not a "how to" of inclusive education. When an opportunity arose at quite short notice, we wanted to make a start on capturing some of this wisdom to make it available to the next generation pursuing inclusive education. Our thanks and gratitude to the people who were able to take up this invitation and wrote or updated their articles or responded to this request.

This collection of stories has been written both for those already convinced about the value of educating all children together – and for those not yet sure how this could be possible. We imagine this collection will be read by parents who are seeking to build their knowledge and confidence to pursue a life for their child that is embedded in their local community. We hope it is also read by parents of children who don't have disability, educators, extended family members and friends, policy makers, professionals, family support providers, unions, academics, advocates and indeed by anyone with an interest in education of students with disability. Inclusive education is everybody's business!

Margaret Rodgers
CEO, 2020.
Community Resource Unit.

FOREWORD

As a young parent, I soaked up the stories of the parents who had gone before me on the journey of navigating inclusive education. I listened intently on what they identified as the “traps for young players” and became alert to advocacy principles and strategies which had stood the test of time. While I was still developing my own advocacy voice as Sean’s mother, I tried on the words of other parents to see if I could make them my own – and doing so gave me more confidence and strength in those early meetings at childcare, kindy and school. While I may have been seeking the 10 step plan for blitzing school advocacy, I learnt to appreciate the value of stories and the generosity of those who shared them. Critically, I learnt that I wasn’t alone and would not be.

The vast majority of contributors to this collection are families – parents, young people with disability, a sister. Families arguably have most “skin in the game”; they need, more than most, for our schools to welcome, include and support all learners. The families who contributed stories would not see themselves as experts in inclusive education, just ordinary families trying to navigate the system as best they can, but they have many valuable insights to share about pursuing the inclusive path. The graduates and families (with young people from Prep to adulthood) are joined by allies – educators, academics, a friend – who also care deeply about inclusive education and see it as “better for everyone”. We include their contributions to harness their perspectives but also so families know that there are steadfast allies who are similarly committed to the pursuit of full inclusion. It does not claim, however, to be a complete or representative collection of Queensland perspectives on inclusive education. Indeed, this project was gestated in the time of COVID-19, when workshop cancellations freed up some resources. The final contributions reflect those who were able to meet our strict deadlines. We are very conscious of missing voices and perspectives, just as we are deeply grateful to all those who graciously shared their experiences.

We want these stories to inspire readers about what is possible – we especially hope that families of children and young people with disability who read this collection will believe with greater conviction in the beauty and power of an inclusive education. Over and over again, these stories remind us why inclusion matters, what it brings to the life of a child, indeed, how it changes lives. We hear about the value of friendships and belonging, and opportunities to learn and participate fully in school life and enjoy ordinary rites of passage. We hear how inclusion feels right, natural, and is simply what every child deserves.

Inclusive education is not a fantasy as some would claim. These stories are clear on that. But the stories are not fairytales – all of the contributors are aware of the very real gap which exists between the full promise of inclusive education and the daily reality for many students. Knowing that that gap exists, while disappointing and even painful, is critical for family advocates; being alert to the likely slippage into less ideal practices can help us re-focus our advocacy efforts. Being forewarned is to be forearmed. With information, good mentors, and “practice”, families can build their advocacy capacity, as one contributor termed it their advocacy “muscle”, and persistently push for better.

Over and over again in these stories, contributors emphasise the critical importance of holding a vision – for the child and for the future of inclusive education – and of the need to never stop believing in the value and worth of every person. Families share how they have learnt to proudly proclaim their son’s or daughter’s gifts to the world. We hear as well of the value in finding allies and supporters – within school systems, within your local community, and within the family advocacy movement. We hear of the guiding principles and specific advocacy tips that families have found valuable in keeping on the inclusive path, and their thinking about the place of school inclusion in building a rich, included life and more inclusive communities.

Two of the contributors, Milly Fisher and Nia Michellis, have contributed their reflections on the education experience of my precious son, Sean. Milly is Sean’s sister and Nia is Sean’s friend of almost two decades. At its worst, Sean’s “inclusion” involved being only offered one hour attendance a week in preschool, being rejected by three high schools, receiving a bill for his support costs due to his being an “economic burden” to his school, being repeatedly told he was in the wrong place, and being threatened with suspensions until we would “have no option but to leave the school”.

These are not small things – they are examples of unacceptable discrimination – but they are not what defines Sean’s inclusive education story. Instead, as Milly and Nia point out, Sean has a rich ordinary life with a strong sense of self, a wide friendship network built over those school years, skills which led him easily into paid work, and his own memories of school which, despite hard times, are overwhelmingly positive and uplifting. If I was telling my story, I would echo many of the contributors who have identified that their advocacy was 100% worth every effort. I have absolutely no regrets about persisting on what was at times a decidedly rocky inclusive education path. Sean’s life at 25 shows me not only that inclusion is possible but also reminds me of the value of clinging to inclusive education as a natural foundation to a rich inclusive life.

CRU’s colleagues from Inclusion Alberta, Anne Hughson and Bruce Uditsky, have spoken about good family leaders as being those who were prepared to “humble themselves to the learning”, essentially able to recognize the good sense of reaching out to those who have gone before – the pioneer parents, allies, and especially people with disability themselves – from whom we will, if we listen, learn how to successfully achieve good inclusive lives and also keep building a movement for social change. For this reason, we have intentionally sought voices of past students and family leaders previously active in inclusive education. And we note that this collection is written not just so families can do their own individual advocacy, but to support those who want to join together to work for school communities which welcome all. Many contributors have noted the critical importance of peer networks – to learn, to console, to bolster each other, to press for change – and we hope this collection may encourage others to join and nurture this family movement for change.

It is scary to think that I started learning about inclusive education a quarter century ago. Progress IS being made – but inclusion should be easier! Our schools are better and stronger in every way when everyone is there. We have known that for a very long time. The research evidence of the benefits of inclusive education is overwhelming and spans a half century. I find it heartbreaking and somewhat incomprehensible that given that evidence, we still have not broken historical habits of separating children with disability from their peers and communities. With the clear direction of the UN Convention on the Rights of Persons with Disability, the transformation of our school systems should occur with much greater urgency and pace. The costs of being complacent about the speed of change is very real. The costs to parents of advocating for what other students and families take for granted remains significant. Painful discrimination still causes damage to students and families – but more than this, exclusion is a loss for everyone.

Deep lasting change will only happen with a transformation of hearts and minds, and the building of a movement of people prepared to stand strong in proclaiming that inclusion is every child’s birthright. Our children and our communities deserve nothing less.

Through sharing these collected stories, we hope to contribute clarity about the values and principles of inclusion and knowledge on how to advocate for inclusion. We want to empower families with greater confidence, and offer a strong reminder that together we are stronger.

Dream big, stand strong ... stand together!

Lisa Bridle

Families for Inclusive Education Project,
Community Resource Unit.



THE GRADUATES



“ I LOVED GOING TO SCHOOL WITH MY BROTHER AND SISTER. IT WAS A GOOD SCHOOL AND I MADE LOTS OF FRIENDS – THEY ARE STILL FRIENDS. ”

Bobby Pate

Free as a bird - Dare to dream and live the dream

BY BOBBY AND TRACY PATE



“ AS PARENTS AND CARERS OF CHILDREN WITH A DISABILITY WE MUST NOT “WRITE OFF” OR DISMISS TEACHERS AND SCHOOLS ... AT TIMES WE HUNG IN WHILE PEOPLE WERE LEARNING.

AT TIMES SOME STAFF AT BOBBY'S SCHOOL MAY HAVE DESCRIBED ME AS “SCARY”, HOWEVER IF WE DO NOT CHALLENGE THE STATUS QUO, CHANGE WILL NOT HAPPEN. ”

Tracy Pate

Bobby Pate graduated from school in 2019 and prior to coronavirus was working in 2 jobs in customer service. Bobby is a strong athlete and has always participated in a number of sports. Bobby is also creative having played piano and drums and now enjoying acting. He has also brought joy to many people through his artwork. Bobby is community minded and enjoys time with his family, friends and extended family.

Following on from a successful career as a senior investment adviser, Tracy Pate has dedicated her time to raising her children, Annie, Molly, Bobby and Jack. Tracy has worked in a voluntary capacity in the disability sector since her son Bobby was born. Tracy is motivated by, and strives for, an inclusive society in which children attend an ordinary school with their peers. She also believes it is important to recognize that people with disabilities and their families are the drivers of a “good and ordinary” life.

BOBBY PATE

My name is Bobby Pate, I am 19 years old and finished school last year. In my family is my mother, my father and two boys, me and big boy Jack and two girls, Annie and Molly. We have two dogs, Patch and Pipi (a new puppy). I love talking to people and going out. I love dancing. I like being strong, now I bike ride for 30 or 40 kms. I put on my alarm, wake up and put on my long pants and jacket. I ride with big fella Cammy.

I like going to the Uni library and doing some art work or my online TAFE course. I run into friends from my different schools at the café. I want to go to Uni more, I get the city cat to Uni. Before coronavirus I liked going to work and make coffees, meet and greet people. I like swimming in the morning at the Valley. I get a bus to my other job as a dispatch officer. I am poor now since coronavirus because I am not working.

I loved going to school with my brother and sister. It was a good school and I made lots of friends – they are still friends. I liked making things out of blocks with some of my friends. Going for ice creams after school and sleep overs.

Nudgee Junior – it was a big school with lots of boys. My friend Max also went to Nudgee Junior; we played “spotto” in the car trip to band practice. After school I went bike riding for triathlon training, it was fun being with the boys.

Ambrose Treacy - a good school, lots of new boys. I like talking to them. I liked the school work and doing the presentations. It was fun catching the train to TAFE in year 11 and going to lunch at Southbank. Then I would go to Indro [Indooroopilly Shopping Town] to meet friends and go to watch the boys play basketball on Friday night. My favourite memories were hanging out with friends.

Sometimes I was treated badly by adults at school. It was hard when the adults sat beside me for my classes. I like doing the work myself. School would have been better if I worked with the boys. At school sometimes I didn't speak much if the adult was sitting beside me in class. I am glad I went to my schools, I like hanging out with my friends.

Sometimes school is hard. I like being out of school, being independent and working in my jobs. Now I can live the dream – go out to parties, work, make my own plans.



“ I LIKED THE SCHOOL WORK AND DOING THE PRESENTATIONS ... MY FAVOURITE MEMORIES WERE HANGING OUT WITH FRIENDS ”

Bobby Pate



“ AS A PARENT I LEARNT TO AIM HIGH AND SLOWLY OTHERS WILL JOIN WITH YOU. ”

Tracy Pate

TRACY PATE

From an early age we had a vision for Bobby of what we wanted for him and what we didn't want. Part of that vision was to be educated in an ordinary school with others in the community. This was one part of our big vision of an ordinary life doing ordinary things. No doubt this journey for us and Bobby has been harder than for our neurotypical children. However, as a recent school leaver we have no doubt that it will lead to a richer and fuller life in the years ahead.

On the last day of school, Bobby commented that he was “as free as a bird”! Witnessing Bobby's belief in himself to grow and continue to thrive in the big wide world of post school is so exciting as a parent. As he confidently led his cohort through the farewell tunnel on his final day of school he is well equipped for the journey ahead.

As parents of a child with a disability you have to be very strong advocates. His Prep enrolment was the first of many experiences of school gate-keeping for our family. At the core of our vision was for Bobby to attend the local catholic primary where many of his friends were enrolled and over 30 of his extended family had attended. This was the place where he belonged. However, we were told by the school “there are special places for children like that”. Various contacts, networks and friends supported us through over a year of negotiations and the eventual enrolment in the school. It was worth persisting; many of his friends from that school are his best friends today.

Our experience of schooling for Bobby was playing the long game. His life outside school was as important as school - club rugby, swimming, bike rides, music and drama productions. As parents and carers of children with a disability we must not “write off” or dismiss teachers and schools. We need to support and encourage schools to develop skills in the area of inclusive education. At times we hung in while people were learning. It is hard work but the reward for your child will be great.

At times some staff at Bobby's school may have described me as “scary”, however if we do not challenge the status quo, change will not happen. As a family we worked hard at maintaining a positive relationship with the school and developed many allies within the school community. When being an advocate I find it helpful to express clearly and often what is important for our family and our dreams for Bobby. I loved sharing and talking about his wonderful gifts and attributes, often recounting stories highlighting his sharp wit, empathy and emotional intelligence. Sometimes people can't see past his disability particularly in environments like schools that are essentially institutions. Most importantly I never lost the absolute belief in him as a person – and nor did our family.

From a young age Bobby would closely watch and imitate his peers. He would learn more from his peers than from adults. I wish I had been stronger in advocating for teacher aides to be used to assist the teachers in the classroom rather than being a “student aide” during his schooling. When teacher aides sat beside Bobby in class he lost confidence in himself and it was harder for him to develop friendships. His teacher aides were all nice people, however, they are not qualified teachers. The appropriate use of this resource is critical for inclusion.

At times teachers were challenged by the idea that a student with an intellectual impairment could achieve academic outcomes and enjoy learning. As a parent I learnt to aim high and slowly others will join with you. It was a great academic achievement for Bobby to achieve a Queensland Certificate of Education (QCE) at the completion of year 12. Consistently we were told that attaining the QCE would be impossible. School was one part of Bobby's life but certainly not the most important. You have to dare to dream to live the dream!



“ GOING TO AN INCLUSIVE HIGH SCHOOL MEANT I BECAME A STUDENT, A WOMAN WITH DREAMS, HOPES AND A DRIVING FORCE. ”

Jamie McCaffrey-Creed

I am a woman with dreams, hopes and a driving force

BY JAMIE McCAFFREY-CREED



Jamie is an energetic 23 year old woman and her hobbies include fitness, yoga, music, friends, dancing, wine and playing with her dog Zeus. To communicate, Jamie uses a range of tools and technologies while she continues to work on strategies to make her verbal speech more reliable. Jamie completed senior high school and gained an OP, which allowed her to study at University. Jamie is a young woman who likes to be recognised for her intellect, and her ambitions are to attend university, while studying areas of interest such as psychology and neurophysiology. She is passionate about all young people being included in society and knows from lived experience that this starts with inclusion in your local mainstream school.

For me, the first few years of primary school were the worst when I was trapped in a Segregated Education Unit (S.E.U). I had a lot of struggles when I started my education, as the school had low expectations and made dangerous assumptions. The Senior Guidance Officer told Mum I was profoundly intellectually impaired, thankfully Mum didn't believe her. The head of the S.E.U. wouldn't support my communication, and the staff refused to use my communication device. Once I moved to our mainstream local state school, life did improve for me. I was at the same school as my younger sister, Kellie, which was amazing because we got to travel to school on the bus together and I had her company while I got to know the other kids.

Even though things were better, this new primary school still wasn't inclusive enough for me. I was only allowed to attend part-time for many years. It was hard because I felt excluded from a lot of things, such as not being allowed to attend Year 7 camp. This exclusion was heartbreaking because I just wanted to do what everyone else was doing.

“ BY ATTENDING MAINSTREAM SCHOOLS, I RECEIVED A HIGH QUALITY EDUCATION AND CREATED LIFE-LONG FRIENDSHIPS.

MY FAMILY CHOSE INCLUSIVE EDUCATION AS THEY BELIEVED I DESERVED THE BEST LIFE HAD TO OFFER. ”

Jamie McCaffrey-Creed

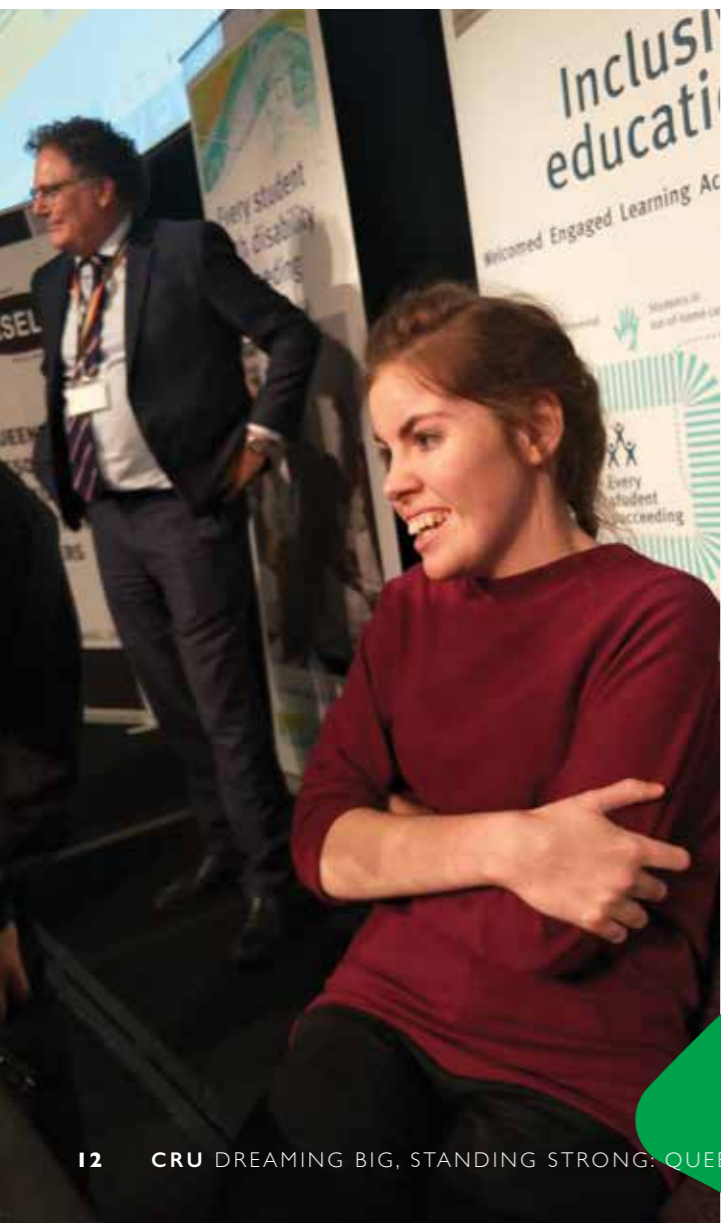
Being excluded had a significant impact on me, which resulted in a low sense of self-worth and feeling like I wasn't good enough. I felt like I was never going to be fully accepted in this school.

In the future, to help students with a disability feel more included, educators should put in the effort to figure out how students can do what they want to, as it is their education. Let them go to camp so they can have those experiences and memories with their friends and peers. I want students with disability to be included in all aspects of school life, and be given the same social and academic opportunities as everyone else. Inclusion is not about being locked up in a special education room! I think overall, if I was in a more inclusive primary school, it would have been better.

Attending an inclusive high school meant that I had an excellent education, as there were high academic expectations and I made friends. With the support of the school and teachers, I was able to apply my love of learning and work hard to receive the OP [tertiary entrance score] I wanted. It was great to get an OP because I went to University for a few years and still have the option to get back into further tertiary education in the future. At school I made friends with a great group, some of who I'm still in contact with today. We got to know each other better because we spent time together at school and outside of school. I wouldn't have gotten to meet people who have similar interests to me if I had been segregated in a special school.

Highlights of high school were when we all attended formal together, went to parties as a group and when I hosted social get togethers too. I probably wouldn't have had those opportunities if I didn't go to an inclusive school. Being in an inclusive high school meant I got to do things I wouldn't have done otherwise, such as finally getting to go to camp. In High School they expected me to be at camp and worked out how it could happen.

I studied subjects that interested me and engaged my brain to learn complex things such as physics and philosophy. My brain is active, so I need to provide it with good information and ongoing learning. In a non-inclusive school the subjects were easier, and I would feel so bored. I liked doing the same content and going to the same classes as my peers. My hard work resulted in me being granted a silver academic award and an encouragement award.



“ACADEMIC AND SOCIAL OPPORTUNITIES OCCUR IN THE LOCAL SCHOOLS, WHEREAS SEGREGATED SETTINGS PROMOTED EXCLUSION.”

Jamie McCaffery-Creed

My family chose inclusive education as they believed I deserved the best life had to offer. They felt that excluding me from the local school and community would be detrimental to my development as a person. After a lot of research, it was decided that all children belong together. Academic and social opportunities occur in the local schools, whereas segregated settings promote exclusion. My family were so passionate about my inclusion that they had a human rights lawyer involved at one point to ensure I could enrol in my local mainstream school. My family offered a lot of support to the school, in order to ensure my success there. They also hosted many fun get together at my place to help me make friends. Going to an inclusive high school meant I became a student, a woman with dreams, hopes and a driving force.

My life is amazing, however I still experience exclusion in some areas of my life. I don't always get included in the social activities that I want to. I think people don't always invite me to participate because I'm different and they maybe make decisions on what they think I can and can't do. To me having friends and a huge social life is important as I love to be included. Social opportunities are vital for someone's happiness. As well as this, University was harder for me than other people. I had to justify my intelligence and the students treated me differently. They wouldn't talk to me directly and instead talked to my communication partner like I wasn't there which hurt my own confidence in my abilities.

I know the students and the administration tried, but it wasn't enough and there was insufficient adjustment for me to be able to successfully continue at this time. Most lecturers and tutors were great but the Head of Faculty didn't believe in me and what I could accomplish with some support from a communication partner. Without the support of the institution, I couldn't remain at University but it is still my goal to return to academic study in the future.

By attending mainstream schools, I received a high quality education and created life-long friendships. Due to not being able to rely on my speech to communicate, it was essential that I had the opportunity to develop my literacy skills for expression at school. From this, I was able to engage in high academic level subjects and make strong social connections too. Having friends let me explore all the fun and interesting parts of teenage and young adult life. Unfortunately we still have a long way to go to achieve genuine inclusion in our schools and communities, but to move forward I think there must be an expectation for inclusive education at all schools.

I'm super proud to be contributing to this resource and hope that it provides comfort and direction and support to families.

THE EARLY YEARS



“ BEING EXPLICIT ABOUT OUR EXPECTATIONS HAS ALWAYS BEEN OUR GUIDING PRINCIPLE WITH VIOLET, BUT OFTEN PEOPLE HAVE NOT EXPERIENCED THE WAY WE VIEW INCLUSION OR UNDERSTAND WHY WE BELIEVE IT TO BE SO IMPORTANT. ”

Shalee Gregson-Quinn

Our dreams for Violet are all ordinary dreams

BY SHALEE GREGSON-QUINN



Shalee is the proud mother of two children who considers herself fortunate to live in a tiny piece of paradise called Yeppoon. Shalee's experiences as a parent, advocate and support person within the community have informed her belief that honouring the knowledge, skills and lived experiences of people with disability helps ensure that we aim for what is possible - not just what is adequate. Shalee has just completed a degree in social welfare, and she likes running, drinking tea and listening to TED talks in the shower.

“ OUR DREAMS FOR VIOLET ARE ALL ORDINARY DREAMS. ”

Shalee Gregson-Quinn

From when Violet was born, I knew that she wouldn't go to a special school. If she couldn't attend a mainstream school, I wasn't sure what we would do. I didn't know much about inclusion in education then, but my thinking was always that I wanted her to have the same opportunities as other children and not automatically be relegated to some separate space. It wasn't complex at all – she needed to belong and that is what has guided us. We went to a gathering for families with children with Down syndrome when Violet was 9 weeks old and it was held at the local Special School. We walked in the gates and it was predominantly concrete and high fences, not the schoolyard we pictured for either of our children.

I was devastated but that strengthened my resolve. Not long after, I went to Centrelink to enquire about disability supports and once we had registered the CSO said “other than that, just come back when she's 16 and she can have the disability pension”. Again, devastating. I felt angry that this was the extent of what some people could see as her potential, even as a tiny baby! I had a long one-sided conversation with Violet on the way home about how one day we would operate a small enterprise together and nothing would hold her back. And then I saw a workshop that CRU was hosting about young people with disability living happy, purposeful lives, which was exactly what I had been envisioning. It was an introduction into other workshops and conferences on inclusion, the chance to meet families with children that were older, hearing their stories and knowing that inclusion can work for all children despite lots of different challenges.

Meeting other families and disability advocates like Marlina Katene, helped me more concretely imagine possibilities for Violet and stay connected. There were also some standout speakers, such as Lisa Bridle and Rhonda Faragher that allowed me to learn from their examples and to recognise what we were pursuing was not only proven educational best practice but a recognition of Violet's human rights.

Daycare and Kindy exceeded our expectations as both embraced diversity and had a focus on play-based individual learning outcomes.

Before she began we documented our vision for Violet:

We envision Violet living a life of choice. We envision her having relationships she feels are valuable. In her future, we envision her doing work that she enjoys and makes her feel productive. We envision our daughter living a happy and meaningful life surrounded by love and support.

In an educational space we hope that sharing a vision statement:

- gives Violet a personality rather than a stereotype;
- is a quick reference guide for others in the learning space as to what to expect or encourage, so we keep it clear and concise;
- invites collaboration to explore goals and establishes the positive direction we see her life taking;
- keeps the language positive, direct and personal.

We update this every year to keep it relevant.

Daycare and Kindy did have some challenges, but we had such positive relationships that we were able to discuss any issues as they arose. I firmly believe that you need to investigate the options and have high expectations around what early childhood education can offer your child.

“ IT WASN'T COMPLEX AT ALL – SHE NEEDED TO BELONG AND THAT WAS WHAT HAS GUIDED US.

Shalee Gregson-Quinn ”

“ INCLUSION IS MORE THAN JUST BEING THERE. ”

Shalee Gregson-Quinn

“ TO US, SCHOOL LIFE IS ABOUT MORE THAN JUST CURRICULUM.

”
Shalee Gregson-Quinn

“ IT WAS EXACTLY WHAT WE HAD HOPED FOR – THAT PEOPLE WOULD KNOW HER BY NAME, AND THAT SHE WOULD FEEL A SENSE OF BELONGING. ”

Shalee Gregson-Quinn



Inclusion is more than just being there - focus less on the disability and more on what your child is capable of doing or what they enjoy and emphasise those things. When things are so personal to you, you can analyse it from so many angles, and spend a lot of time thinking about the best way to approach things. Having allies or a sounding board can help, as well as some guiding principles.

As well as setting high expectations, our other guiding principles are:

- Does her brother do it?
- Are other kids doing it?
- Does it feel right?
- Is it in line with our vision (is it going to benefit her)?

We were keen for Violet to attend a school where inclusion and working cooperatively with parents was part of the culture, because we recognised this as essential from early in her life. The culture of inclusion flows from the top down. With her older brother already attending the local State school, we were able to visit a lot prior to enrolment, which helped Violet get acquainted with the staff and students, along with some of the expectations of being at school. She attended dance classes, sports days and assemblies at school like any other sibling, and we ensured she did those things to make connections and be seen as a little sister and family member first. It was heart-warming on her first day of school walking in the gate and hearing multiple children and parents calling out “Hello Violet”.

It was exactly what we had hoped for – that people would know her by name, and that she would feel a sense of belonging.

The Principal, Violet's teacher, and staff of our school have been open and communicative from the start. They have welcomed Violet, invited our input and are working as a team to support her as an authentic member of her class. I have seen so much growth already (only a few months in) in terms of her independence, speech and confidence. To us, school life is about more than just curriculum. The staff have spent a lot of time supporting Violet to build routines into the day and she's taking on more responsibility than I would have expected her to as a 5 year old.

I have always been mindful that teachers have the daunting task of educating a diverse group of students each year and it's easy to feel like you are asking too much of others when inclusion feels hard. However, when you consider that students attract significantly more funding to attend a segregated setting, it just makes me feel angry. If State schools were resourced adequately to allow teachers time to focus on their core role of educating, all students with disability would be supported adequately too. But while investment is made in a dual track system I don't see how that will change.

Over the years I have witnessed other families face demoralising experiences and challenges in the education system and that makes you wary. Being explicit about our expectations has always been our guiding principle with Violet, but often people have not experienced the way we view inclusion or understand why we believe it to be so important. To those people I would say: read the research. And understand how segregation impacts people who aren't part of their local community, seen and known. Inclusion takes work, but it is a reflection of our diverse society.

Our dreams for Violet are all ordinary dreams. We want her to have a part time job in high school and try the things her peers are doing. To be supported when she needs to be, and independent when she can. Our hope is that one day Violet will be viewed by the whole of society as an equal, worthy of the typical things life has to offer. And that she's happy, healthy, and fulfilled.

“ BUT WE STARTED TO GET MORE EDUCATION - LOTS OF READING AND TALKING TO OTHER PEOPLE, WE WENT TO LOTS OF CONFERENCES. ”

Shahram Jazan

“ AT THE BEGINNING, LIKE ANY REFUGEE, YOU GO THROUGH THOSE FIRST STAGES LIKE ISOLATION, LACK OF LANGUAGE, LACK OF SENSE OF BELONGING TO THIS COUNTRY. AS WELL AS THIS I ALSO HAD MY OWN DISABILITY OF HAVING A VISUAL IMPAIRMENT. LIFE WAS VERY HARD FOR ME. ”

Shahram Jazan

Life is full of challenges, but I don't break easily

BY SHAHRAM JAZAN



“ IN AUSTRALIA, THERE ARE LOTS OF SERVICES, ORGANISATIONS AND RESOURCES, BUT NAVIGATING THESE SERVICES FEELS LIKE YOU REQUIRE ANOTHER 'DEGREE'. ”

Shahram Jazan

Originally from Iran, Shahram Jazan is a social worker who works as a case manager at Multicultural Australia. Since arriving in Australia, Shahram has attained a Diploma in Counselling and Mental Health and a Bachelor of Social Work. Shahram has been involved in a number of community organisations, and was an inaugural committee member, now President, of AMPARO Advocacy and has also been a committee member of the National Ethnic Disability Alliance. Shahram has provided volunteer support at Sporting Wheelies and the Australian Red Cross and has represented Queensland numerous times at the National Goalball Championships. Shahram has shared his story in a number of forums as a person with vision impairment who has overcome many obstacles.

I am originally from Iran, coming to Australia in 2002, and I am also blind. I have Retinitis Pigmentosa (RP) so I have navigated life as a person with disability for some time. It is an inherited condition, and though I was born with it, my vision has deteriorated over time.

My son was confirmed with an ASD diagnosis when he was approximately 3 years old. At first I was just a Dad in denial, thinking no, he doesn't have a problem, and when he got his diagnosis I had difficulty accepting it at first. For his Mum it was different, she more quickly accepted it and started looking at what we needed to do next. We started doing a lot of reading about how we could help him because he had some language delays and we were very worried.

The whole diagnosis process was quite hard. Certainly we noticed a language delay for a while but some people were saying that his language delays were because I speak three languages at home, Arabic, Farsi, and English, which we were teaching him. As his parents however, we sensed that there was something going on.

We decided to investigate through QLD Health (which we found to be a disaster) to obtain a diagnosis. During our first consultation with the Community Health Centre, they said "oh he doesn't have any problems, he's just one of these boys". I was very upset and was wondering "what does one of these boys mean"?

I asked for this decision to be reviewed by the paediatrician. They said that it wasn't needed. We just couldn't leave this. Once my wife and I are decided, we are determined. We are very lucky that as we are both working, we have the financial ability to consult with a private paediatrician who, after one or two consultations, determined that yes, our son had ASD.

“ I MYSELF WENT TO A SPECIAL SCHOOL WHEN I LIVED IN IRAN AND I DON'T BELIEVE I LEARNT THAT MUCH THERE, SO I WANTED SOMETHING DIFFERENT FOR MY SON. ”

Shahram Jazan



It was a very bad feeling for us, especially because of my own background and my own disability. I thought, oh gosh, I have a disability myself and now I have a son with a disability - I just thought it would be chaos... and doubly hard.

But we started to get more education - lots of reading and talking to other people. We went to lots of conferences. We met a doctor at one of these conference who also has ASD, as well as a Maths teacher with ASD, so we started to get a different picture of what autism means.

My son at the moment plays tennis (he's really good), he does swimming, horse-riding, he's a good soccer player, and he attends school which he loves. After lots of early intervention, meeting other people, seeing a psychologist, he's doing pretty well and it is much more positive than I imagined. He is able to do a lot of things very well on his own and it is a credit to my wife who has done a lot to help our son.

I am very, very aware though that things are not always easy for people who come to Australia as refugees and asylum seekers, or for anyone who doesn't have good English skills. I've always been surrounded by very loving and caring people who have believed in me, but I had my own struggles. I came to Australia in 2002 as a refugee/asylum seeker. At the beginning, like any refugee, you go through those first stages like isolation, lack of language, lack of sense of belonging to this country. As well as this I also had my own disability of having a visual impairment. Life was very hard for me.

At first, I was a person who didn't know English, I was trying to fit into the society. Because society does not know you, there is no opportunity. With a disability there was less opportunity. As a refugee you don't have the right visa to access anything. I lived for 3 years on a TPV (Temporary Protection Visa), so no TAFE, no education etc. When I compare my life as a refugee back then to today's refugees I see that they have many more opportunities which we didn't have back then. It was very hard and felt like it was our punishment for coming the way we did to Australia.

It was terrible. Many times I blamed myself for making the decisions I made, but really we didn't have any choice.

I was determined and went to a TAFE to learn English. They said "we never had a person who is vision impaired and cannot speak English". And then, because of my visa type, they couldn't give me any support. So I decided to teach myself English. I started building a friendship network through my involvement with sport (for blind people). These people became my friends and the friendship built from there.

I remember meeting a guy in this group who was blind and a lawyer, and it really shook my expectations and gave me hope. With great difficulty, isolation started to ease and I decided to get books in braille, was introduced to Braille House, and met other people. We used cassettes to learn English (I also obtained newspapers in Braille) and I was learning to speak English like Australians.

I started my formal studies at Southbank TAFE in 2004. At first, they told me I couldn't study there because of my vision impairment. I enrolled for Certificate III in Community Services and it took me six months to complete this. Every night I was crying because I couldn't understand what they were saying. I was recording the lectures and listening to them at home. It was very tiring. After some months I was able to understand more what was going on.

With great difficulty, I was able to complete my Certificate III. I then thought a Certificate III is nothing and that nobody would give me a job with this. People were telling me to do Aged Care, and I thought that without vision I couldn't so easily do this line of work. So I decided to keep studying doing a Certificate IV in Community Services. When I finished this Certificate I was introduced to AMPARO Advocacy and this allowed me to do some community work.

Then I embarked on a Diploma in Community Services. Undertaking studies with English as second language plus my disability was very difficult. When I finished my Diploma, I started looking for work. However, all the jobs I applied for needed things like a drivers' licence. Instead of persisting with job hunting, in 2008 I decided to do a Social Work degree at QUT. I really think this was the right decision to go to university and start this degree because I wouldn't be here without this degree to be honest.

In 2011 I started at MDA (now Multicultural Australia) and did 6 months in a student placement role. One day, the CEO, Kerrin, approached me and said I was "doing an amazing job with the refugees" and also that there was a locum position becoming available if I'd like to apply for it. This was the best news - that someone in this country was able to recognize my hard work! That's where I started at the Humanitarian Support Program as a Case Manager. Finally I had a paid job as a social worker.

My own experiences make me very aware of how totally different the Australian education system is for many refugees and migrants. For me, it's a totally different situation compared to Iran. In Iran, if you have a vision impairment, you go to the school for the visually impaired. There aren't many opportunities or services.

In Australia, there are lots of services, organisations and resources, but navigating these services feels like you require another 'degree'. I have friends who have children with disability who find it difficult as those parents still struggle with English, and they struggle with navigating the NDIS or knowing the school processes. They are scared and don't feel empowered to navigate the system. We have great services but people in our community experience difficulty understanding them. For people who have lived in a dictatorship, they don't know they have choices, they think someone in authority will come and tell them what they must do. We have to connect people together so they understand their choices and can explore options for their children with disability. Whilst there are people who cannot communicate in English and cannot understand the system, advocacy will always be needed. We still have people who are more vulnerable within the community.

People with disabilities have often been treated poorly in our home countries, and certainly back home, people isolate their children with disabilities because they have no expectations. If people don't change their expectations, this can really limit the children, even in Australia. I really encourage people to get out into the mainstream community, to volunteer, and to expand networks beyond their immediate family. I was lucky to find a mentor, someone who is blind but is a lawyer with a PhD. Of course, not knowing English will cause a lot more issues. The challenges I faced have made me very resilient. I don't break easily, I feel independent and I'm able to help others that have disabilities.

When families have a member with a disability, I know that a lot of people are scared, a lot of them are scared of things being any more complex and are happy with simple things like having a roof over their heads and so they accept things as they are, rather than questioning. And in many cultures, people struggle with the stigma and stereotypes.

People worry a lot that the community is going to look at them in a different way. I understand this, because when I lived in Iran, I didn't use a cane because I was uncomfortable with how that would be seen. However, I've come to use a cane here in Australia because there is more acceptance. Iran is changing, but unfortunately in other countries this change is slower. For example, in some African countries, there are still issues with understanding what disability is, and having that positive belief in a person with disability.

My own experience living with vision impairment has really informed some of our decisions. For example, the paediatrician told us to perhaps send our son to a special school. I told my wife that I myself went to a special school when I lived in Iran and I don't believe I learnt that much there, so I wanted something different for my son. I thought and still do that my son being in a mainstream school will be very beneficial for him. It was the right decision to do this.

We had no hassle in getting him into the school once we made our decision. The teachers are magnificent. The school has a very good and strong philosophy about being in nature and being a good human being, and this is wonderful for my son. It is a beautiful school.

I want my son to be someone who has a good understanding about people. I want him to be a nice human being and a good citizen for this country. So our choices around school and much more are all directed to those goals. We try very hard to support him to achieve at school and to be that good person. His teacher confirmed to me the other day that he's doing "magnificently well".

To my mind, challenges will always be there. Some parents without children with disability distance their children from the children with disability or other differences. They don't get united and integrate with other families and children. I do worry about it when parents don't want to integrate and teach their kids to accept others. Everyone is missing out on great learnings not just for now but for the future.

My hope is that people with disability are more accepted at a community level. For all the positive changes, there is still a lot of non-acceptance from the general community. I'm still very grateful to be in this country, because you can succeed and achieve in this country.

We have to keep trying our best for changes, keep talking, keep the discussions going, so we can have inclusive communities for everyone.

“ IF PEOPLE DON'T CHANGE THEIR EXPECTATIONS, THIS CAN REALLY LIMIT THE CHILDREN, EVEN IN AUSTRALIA. ”
Shahram Jazan



Inclusion of Eliza: a delightfully straightforward school experience

BY SUE TAPE



Sue's career experience is in auditing, design and implementation of learning and development at a local, national and Asia Pacific level. Sue is now using her career experience in building an inclusive local community around her family. She has contributed to the work of the Queensland Collective for Inclusive Education in a variety of ways. Sue is excited about the opportunities to share her family's story, connect with other families and be a force for change.

“ FOR EVERY CHILD THAT SAYS, “HI ELIZA” AS THEY WALK PAST ...I KNOW THAT ELIZA IS EXACTLY WHERE SHE SHOULD BE. ”

Sue Tape

People will ask me how we are as a family, “how's things?” My standard response before COVID-19 was “delightfully boring and straightforward”. Eyebrows crinkle and I explain “Boring is good.”

We have two children who are three school years apart. Our son had been at school for three full school years before his sister started school, and our daughter Eliza had been front and present at the school that whole time – pickups, drop offs, on my lap at concerts, playing with the other children at the local pool during holidays and birthday parties, noisy like all little sisters at the Christmas assembly, etc.

In the year before Eliza started school, therapists, doctors and other professionals peppered conversations with questions about school preparation and planning. Those questions appeared to be focused on how Eliza would ‘cope’ and what level of effort the school might go to for her ‘benefit’. Knowing my daughter's determined spirit, I often joked that they should be more worried about how school would cope. There was also the constant curiosity as to why she would not attend the special school where she had attended the early childhood development program. What mysterious magic had we based our decision on and how would this work? One question that threw me was how would Edvard explain his sister to the rest of the school? My first instinct was to query why he had to ‘explain her’.

Fortunately, our conversations with the school team were different. Almost all of the conversations started with the question “Is Eliza excited to start school?” Meetings and kindy visits were organised that looked at what Eliza was up to, what she enjoyed about kindy, what sorts of adjustments helped her to interact with her kindy classmates and what goals were we working on at home. I asked a cross section of staff from school, kindy, then Disability Services Team, external therapy, and the Department transition team, to join together for a meeting in a local coffee shop. It was the first time any had experienced this, and it seemed to me to create a sense of excitement and collegiality that they were all to be part of Eliza's transition to Prep.

“ ELIZA LOVES SCHOOL. SHE LOVES THE ROUTINE, THE RHYTHMS OF THE SCHOOL DAY AND THE OPPORTUNITIES TO INTERACT WITH HER PEERS. ELIZA ALSO LOVES THE VARIETY OF SCHOOL. ELIZA DOESN'T SEE HERSELF AS ANY MORE OR LESS THAN A REGULAR MEMBER OF HER CLASS. ”

Sue Tape

These and other subsequent conversations didn't avoid the mundane arrangements that needed to be made and didn't skirt around Eliza's disability. The school team also did NOT start conversations with phrases like "Eliza needs to be doing XYZ before she starts prep....".

When your child is yet to walk, talk, toilet or eat independently, 'preparing for Prep', as so much of the social media calls it, can be a time of fraught emotions as others measure her eligibility on a set of criteria totally divorced from our vision for her; her strengths, her interests and her potential. Eliza's excitement about going to school has never been tempered by any differences between her and her peers. Eliza loves school. She loves the routine, the rhythms of the school day and the opportunities to interact with her peers. Eliza also loves the variety of school.

Before school and with over 6 years of early intervention and medical trauma under her belt, Eliza appeared wary of and weary with adults and their expectations of her to repeat the same linear development milestone driven tasks over and over with the same expected outcome. We were also tired of explaining that Eliza didn't appear to measure her happiness or quality of life by whether she would respond to her name, eat certain food, or say B for ball. People and professionals who were focused on frameworks and forms missed that B is for bath, formula was her saviour; she knows what her name is, and if you are over the age of 20, you are merely a means to an end and should not assume you are her friend.

School recognised, with prompting, the risk of an overuse of adults and that there was no need to position their efforts as 'fixing' Eliza. School also still sees the huge benefit to Eliza, her peers and the staff themselves, of mobilising the other 25 or so class members as instigators and collaborators. Many firsts have been done at school, away from her pesky parents (and yes for the possible adulation of her peers!): first independent steps, first wearing of the hat to play, first consistent use of her speech application etc.

Eliza doesn't see herself as any more or less than a regular member of her class. She lines up, she wears her hat, she borrows from the library, she learns in the classroom, she sits for the morning notices, she stands for Advance Australia Fair, she creates art for the fete, she competes in the cross country, she attends Spanish lessons with great enthusiasm, she gets in trouble for being noisy in assembly, she gets tired of practising the same song over and over for the Christmas concert, and she climbs all over the play equipment with her friends.

“ THERE WAS ALSO THE CONSTANT CURIOSITY AS TO WHY SHE WOULD NOT ATTEND THE SPECIAL SCHOOL . ”

Sue Tape

“ SCHOOL RECOGNISED, WITH PROMPTING, THE RISK OF AN OVERUSE OF ADULTS AND THAT THERE WAS NO NEED TO POSITION THEIR EFFORTS AS 'FIXING' ELIZA ”

Sue Tape



“ THE CONSISTENTLY HIGH EXPECTATIONS OF HER BY HER PEERS, HER TEACHERS AND HER FAMILY, MEANS THAT EVERYONE ... [GETS] SWEEPED ALONG IN THE FLOW OF NOT "IF" BUT "HOW" TO INCLUDE ELIZA PHYSICALLY, TO ACCESS THE CURRICULUM AND SOCIALLY. ”

Sue Tape

Eliza got to this place, year 2 at her local school, because she turned up on day 1, excited, dressed in the same uniform, with her Dad carrying her bag, her things named, and ready to learn. She was welcomed, her needs were anticipated and planned for, and everyone had high expectations of her – academically and socially.

No effort was made to explain to her peers the differences between Eliza and her classmates. There have been numerous delightfully age appropriate questions over the years. Eliza's classmates know disability is a word that they can use and that understanding her differences to them is a natural curiosity. Their attention span on the intricacies of this is also age appropriate! Eliza is short for her age. She is a year older than almost all of them.

She likes to communicate with her voice and her body. Eliza uses a wheelchair sometimes. She has no interest in consuming anything other than formula. She is a super wiz with an iPad. She likes to check out how things feel, taste and smell. She needs adult help to do some of the things that her peers don't. She doesn't need help for everything. She's not interested in craft but loves anything with wheels. Music and water are her favourite things.

And as one Prep peer told me in term 1, "Eliza is awesome at puzzles, don't forget that!" Eliza loves school.

Nobody has questioned whether Eliza should be at school, with her class, progressing from year to year. This solid foundation of inclusion means that conversations are about how to get the best out of Eliza and what's the next challenge for her, not about other "options" for her. The consistently high expectations of her by her peers, her teachers and her family, means that everyone else: new class members, the wider school community, external partners, new team members, relief teachers etc. are swept along in the flow of not "if" but "how" to include Eliza physically, to access the curriculum and socially.

Eliza might not get invited to every single birthday party but for every child that says, "Hi Eliza" as they walk past and every time a classmate says to me "Do you know what Eliza did today....?", I know that Eliza is exactly where she should be.



THE MIDDLE YEARS

“ BELONGING TO COMMUNITY FEELS BOTH REALLY ORDINARY, AND VITALLY IMPORTANT. ”

Lara Maia-Pike



Inclusion benefits everybody...
I don't think we should settle for anything less

BY LARA MAIA-PIKE



“ I CERTAINLY DID NOT SEE MY CHILDREN AS BROKEN OR NEEDING TO GO TO A “SPECIAL PLACE”. I SIMPLY ASSUMED MY KIDS WOULD GO TO A LOCAL SCHOOL, LIKE EVERYONE ELSE

REMEMBER THAT YOUR CHILD IS NOT BROKEN AND THAT THEY DESERVE THE GOOD LIFE LIKE EVERYBODY ELSE. ”

Lara Maia-Pike

Lara is an equity practitioner and mother of two boys, Oliver and Thomas. She has worked in Higher Education for over fourteen years and is passionate about education and social justice. She is a PhD candidate in Inclusive Education with research focusing on transition planning for students on the autism spectrum in senior high school.

Initially, inclusion was not a conscious matter of choice in my mind. I was born and bred in Brazil, so I found that many of the concerns raised by doctors, allied health professionals and educators were often associated with cultural and social expectations rather than my children's capacity to learn and engage with others. While there were challenges, I certainly did not see my children as broken or needing to go to a "special place". I simply assumed my kids would go to a local school, like everyone else. So, at that point, inclusion was not a matter of choice.

We are a family of four, my husband and I and our two children Oliver, 9 and Thomas, 7. I moved to Australia to study in 2000 but after two years living here, I met my husband. We love travelling and did not think about having a family for a long time. Motherhood was a brand new thing for me – until having my own children, I had never changed a nappy in my life!

Both Oliver and Thomas were diagnosed on the autism spectrum and with other disabilities before starting school. I think there was a big learning curve for me particularly, because I didn't have a good understanding of the school system in Australia, so it took me a little while to recognise how exclusion happens here. As I slowly learnt, inclusion requires continuous work with school staff, but it also often involves challenging some assumptions from professionals and the wider community. Oliver completed his kindy year in Melbourne and his teacher at the time did not think he would cope with mainstream schooling. We moved to Brisbane just before Oliver was due to start Prep. While we experienced some gatekeeping trying to figure out our lives in a new city, Oliver's kindy teacher was "satisfied" that he would be ok in Prep because she believed that Queensland schools had lower academic standards than Victoria!

Fortunately, the move to Brisbane enabled us to choose where to live, and to choose a school that encompassed many of our expectations and beliefs. The school we ended up choosing was not our first choice on paper but when we visited the school and talked to staff, it was clear that my kids were welcomed there.

Our experiences have not been straightforward nor perfect. It seems natural to me to be upfront with educators about what supports and accommodations my children may need to be able to participate, but this has led to discrimination. For example, I was once told by the director of a pre-school setting that, based on Oliver's diagnosis, they needed to assess him before they could confirm his enrolment. But being upfront has also led to some wonderful conversations and experiences – seeing staff acknowledging and celebrating my children's strengths and gifts in daily exchanges has been heartening. Other highlights would be more formal occasions such as attending school assemblies to watch them full of pride or receive the "student of the week award". It has been wonderful to watch my children engaging in play and connecting with peers and teachers, growing and learning together, and thriving in a regular school setting.

The main benefit we have experienced from inclusive education is to feel that my children as individuals, and our family as a whole, are part of our local community. Belonging to community feels both really ordinary, and vitally important. My kids go to a very large multicultural school and I love the diversity of cultures and people. I think most families there also enjoy the diversity, so I guess this has made things a little bit easier because people are willing to accept and welcome difference. However, I am acutely aware that cultural inclusion does not equate to inclusive education, so there is still some work to be done!

When I think about inclusive education, I see that a lot needs to change in the system. Unfortunately, there is big a cultural shift that needs to happen in schools and educational institutions, which will not take place overnight. This change will come as we - parents, allies and communities, educate ourselves and take the opportunity to educate others. One step at a time, but I certainly believe it is possible! I already see much of this change in myself as I learn more about inclusion and how I can influence my local networks. You might not see changes in a school term, but sometimes a little change made by one person can help the next child and this is a step forward. It is everyday continuous work.



“OUR ROLE AS PARENTS IS TO HELP THEM DEVELOP THE SKILLS THEY NEED TO LIVE THEIR LIFE TO THE FULLEST. THAT INVOLVES ADVOCATING FOR THEM UNTIL THEY ARE ABLE TO DO IT FOR THEMSELVES.

I AM ANNOYINGLY OPTIMISTIC, AND I DO BELIEVE WE CAN CREATE A BETTER WORLD FOR ALL CHILDREN - INCLUSION BENEFITS EVERYBODY SO I DON'T THINK WE SHOULD SETTLE FOR ANYTHING LESS.”

Lara Maia-Pike

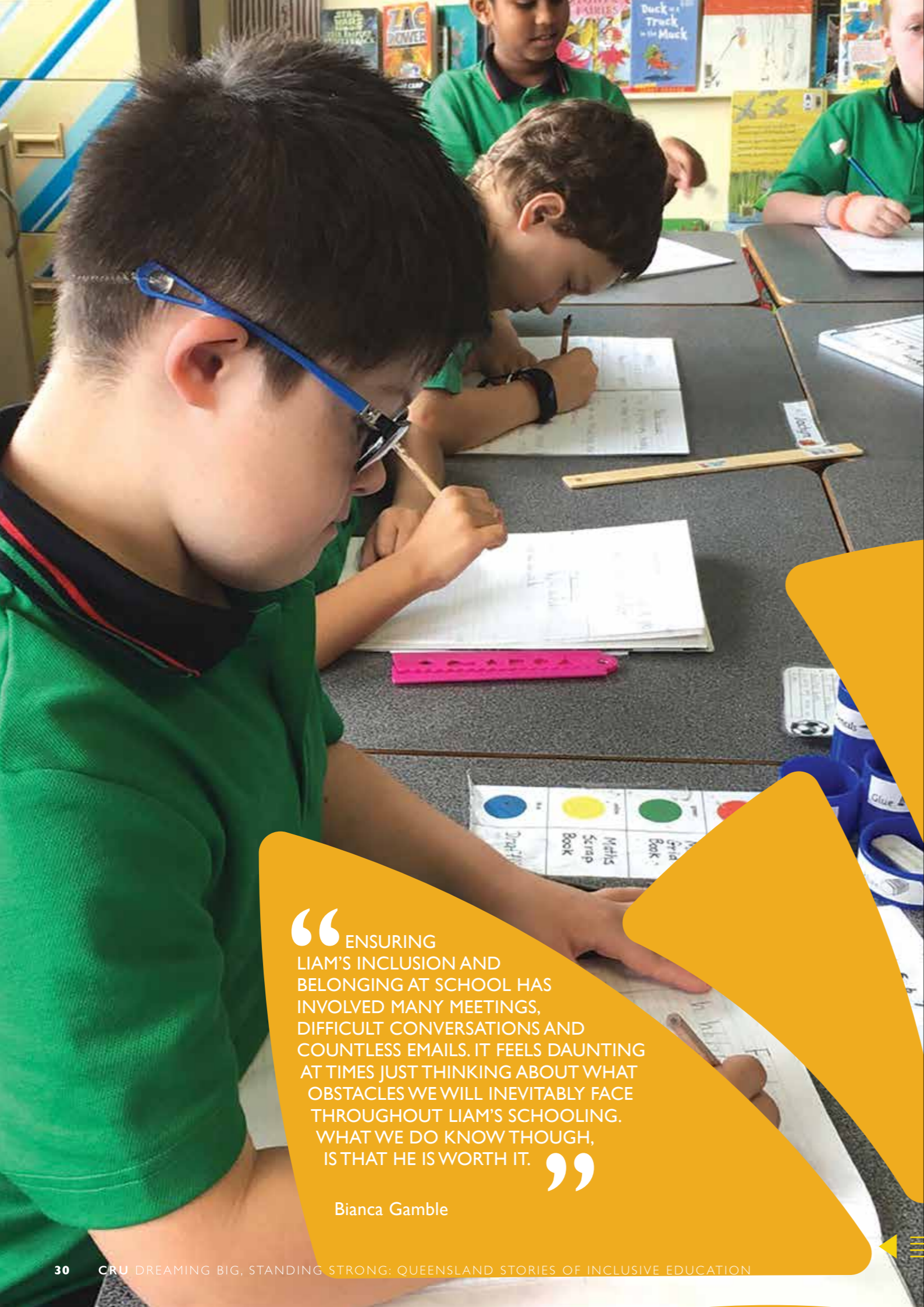
In my professional work, as an equity practitioner in Higher Education, I am often in contact with many teachers. Most of them are very caring people, but unfortunately sometimes teachers may not have appropriate knowledge about inclusion, do not have the right experience or don't receive adequate support to implement it. My hopes are that school leaders and politicians can start putting students at the centre of their decisions – where human rights and ethics come before votes or school performance. I would like to see inclusion move from theory to everyday practice in multiples domains of our society.

To help me navigate inclusion (and keep my sanity!) I often remind myself that most people are actually not educated about what inclusion really means. Unfortunately, the concept of inclusion is muddled up with special education and integration models, so it is often misunderstood, and practice lags behind what we know about inclusion. I find it helpful to think that when people have a flawed understanding of inclusion, there is an opportunity to educate them rather than let my frustration take over. Sadly, at times, educating others might not be enough to change views or attitudes - that's when you join forces with likeminded people to help you get through and challenge some long held assumptions.

Along the way, I have learnt attitudes and skills which help me to be a better advocate for my sons. I think the first thing is to remember that your child is not broken and that they deserve the good life like everybody else. Second, be kind to yourself – you don't have to navigate the system alone. You are being the best parent you can be so it is important to connect with people that can listen to your concerns and can help you navigate systems and situations. Peer support can help you with getting knowledge, build your confidence and develop a vision for a positive future.

Our family has been fortunate to come across many amazing people that have welcomed us, helped us navigate the different systems and supported us to articulate our vision for inclusion. As parents, my husband and I want our boys to grow into independent, confident, kind and well articulated adults. We want them to be proud – we use very positive language at home and both Thomas and Oliver express their pride in being autistic. Our role as parents is to help them develop the skills they need to live their life to the fullest. That involves advocating for them until they are able to do it for themselves. We want our children to have choices. This involves creating a world that is not only better for them but is better for everyone.

I am annoyingly optimistic, and I do believe we can create a better world for all children - inclusion benefits everybody so I don't think we should settle for anything less.



School Inclusion - part of a much bigger picture

BY BIANCA GAMBLE



“ MY ADVICE TO OTHER PARENTS IS TO NEVER DOUBT THE FACT THAT YOUR CHILD CAN BE INCLUDED, PHYSICALLY, SOCIALLY AND ACADEMICALLY ”

Bianca Gamble

Bianca is a proud mother of 4 children between the ages of 1 and 12. She is determined to create full and valued lives for all of her children, including her 10-year-old son Liam who has Down syndrome. She believes strongly in the power of family leadership and works to influence and support others to pursue an inclusive life for their family member. Her current focus is advocacy for all children's right to Inclusive Education. Bianca has a background in Psychology and Human Services, was a member of CRU's Disability Leadership Project advisory group, a founding member of the QLD Collective for Inclusive Education and is a facilitator of the QCIE Inner North Brisbane Peer Support Network.

“ ENSURING LIAM'S INCLUSION AND BELONGING AT SCHOOL HAS INVOLVED MANY MEETINGS, DIFFICULT CONVERSATIONS AND COUNTLESS EMAILS. IT FEELS DAUNTING AT TIMES JUST THINKING ABOUT WHAT OBSTACLES WE WILL INEVITABLY FACE THROUGHOUT LIAM'S SCHOOLING. WHAT WE DO KNOW THOUGH, IS THAT HE IS WORTH IT. ”

Bianca Gamble

Liam is our beautiful 10-year-old boy and second of our four children, as well as a much-loved member of our big extended family. Liam has an older sister Claire and two younger brothers Finn and Ari. He's into basketball, drumming, cubs and anything that involves having fun with family and friends. He has a big personality, loads of confidence, and has the warmest, caring heart.

Our three eldest all attend our local Prep-12 state school, and my husband Michael and I couldn't imagine things any other way.

When Liam was born with Down syndrome we were thrust into a world of disability services, early intervention therapies, specialist appointments and introduced to places like the special school playgroup. While many of these experiences were positive, it also meant that we were confronted by a lot of mixed messages and well-meaning advice. When contemplating school, we honestly didn't know what to think. Not having grown up in an inclusive society, it was difficult to have a clear vision of what his future could look like. A consistent message was that Liam's development would be a major factor in deciding if he would be "suitable" for mainstream education. Despite this not sitting well, at that point we didn't really have a solid rebuttal.

When Liam was 18 months old, I was lucky enough to meet another mum who spoke about her teenage son in a way I had not heard before. She talked about his wonderfully ordinary life, full of typical experiences, and a vision for his future that wasn't limited by low expectations. She described his belonging and inclusion at school in terms of his human right, as opposed to something that was conditional. This conversation not only reaffirmed my thoughts that this is what I wanted for Liam, but also my belief that it was possible.

Liam was 2 when I attended my first inclusive education event. I was exposed to the decades of irrefutable research evidence supporting the social, behavioural and academic benefits of inclusive education. I also heard other parents share their experiences and reasons for sending their children to mainstream schools. I learned that inclusive education has nothing to do with development, academic abilities, speech, behaviour or general readiness. The only criterion that Liam or any child should have to meet is being of school age.

It cemented in my mind what I was already feeling – that Liam deserves the same opportunity to education and life in general, as his big sister, and it probably wouldn't just happen. From there, we made a very conscious decision that we will not let Liam's diagnosis dictate the places that he goes, the things he gets to experience and the type of life that he leads. He will have the same opportunities as his siblings and share those experiences with them, at the same school and in the same community.

Liam went to Kindergarten, rather than ECDP. We wanted his precursor to school to be an inclusive environment where the expected transition for all of the children is to a mainstream school. We decided for him to do a second year of Kindy after moving closer to my husband's work. Our move gave us the opportunity to consider school options and allowed us to do some research. What we wanted for all 3 of our children was to attend their local school, a school with a real sense of community, which valued the diversity within it. We were looking for a school culture and structure where inclusion was more likely.

Knowing how easily segregated practices flourish when there is a "place" for students with disability, we felt strongly that a school with a "unit" was out of the question.

Liam's second year of kindy gave him the opportunity to develop some lovely friendships in our new neighbourhood with children with whom he went on to Prep with. Kindergarten was wonderful and gave us a real insight into the beauty of true inclusion.

Our eldest Claire was already attending the school and was in year 3 when Liam was warmly welcomed into Prep. We have loved watching him learn and grow alongside his classmates, gaining more confidence each year. He is now in year 4 and is having a really positive school experience. He is involved in everything from excursions and sports days, to concerts and music performances. We have been lucky to have some wonderful teachers, who have listened to our vision and worked diligently for Liam's inclusion.



“ WE HAVE BEEN LUCKY TO HAVE SOME WONDERFUL TEACHERS, WHO HAVE LISTENED TO OUR VISION AND WORKED DILIGENTLY FOR LIAM'S INCLUSION. ”
Bianca Gamble

We see friends and social opportunities as being such an important part of the school experience, so encourage and facilitate these as much as we can. For Liam, his inclusion extends far beyond the school gates, and we nurture his involvement in many ordinary community activities as they all put him on a path to a fully inclusive life.

I would love to say that our experience so far has been effortless and without stress and worry. However, the fact is, our education system is not yet a fully inclusive one. Streaming and ability grouping is still prevalent, and the tendency to separate children with disability is still strong. Liam does remain with his classmates for all of his lessons, but this is something we've had to put ourselves out of our comfort zone to advocate for, rather than something we can take for granted. Ensuring Liam's inclusion at school has involved many meetings, difficult conversations and countless emails. It feels daunting at times just thinking about what obstacles we will inevitably face throughout Liam's schooling. What we do know though is that he is worth it.

My advice to other parents is to never doubt the fact that your child can be included, physically, socially and academically. Before embarking on school, I think it's important to be as clear as possible about what authentic inclusion means, what it looks like and how it should feel. I hope that you can walk into your local school with confidence and know that your child has every right to be there and deserves to be included and valued to the same extent as every other student. Rather than directing those initial conversations to supports and funding, we chose to focus our energies on establishing a positive relationship and sharing our expectations for Liam's school experience. We talked about his strengths and assets, giving the school insight into the amazing qualities he has to offer. We have always prioritised getting to know his classmates and their families and feel that these relationships have such a positive influence on Liam's identity and belonging at school. I also strongly recommend being connected with other families who are pursuing or have pursued inclusive education. I personally have benefited enormously from the help and support from other parents and feel much greater strength in the knowledge that we are not alone in wanting this for our children.

I know that inclusive education shouldn't have to take this kind of effort, energy and determination. My hope for the future is that our schools become a place where every child is welcomed and genuinely included without question - with appropriate supports and adjustments provided to enable equal access and participation. I wait eagerly for a time where disability is seen as both natural and something to be valued as part of our community – a time when all of our children get to experience school together.



Attending the Family School

BY SONIA GREENOUGH



Sonia is the mother of seven children aged from 9 to 28. Her 12-year-old son, Cameron, who has Cri du Chat syndrome and her 9-year-old son, Nathan, who has Autism attend the local primary school – the same school that their older siblings attended and which Sonia also attended along with her four siblings. Sonia’s children have been fortunate to grow up as part of a large extended family network. The family shares a passion for travel and holidays. Sonia enjoys cooking and planning the next holiday!

When my first child started school, I enrolled her at the local school – the same one I had attended with my siblings. The subsequent children followed as they became school age. When my 6th child, Cameron, was young, it was recommended that he attend our local ECDP, which we did. Although I dreamt of him attending our local school with his siblings, the ECDP was planning on him attending the Special School. A friend, whose daughter has Down syndrome, told me about how her daughter attended our local, lovely kindy so I enrolled Cameron. Cameron was still attending ECDP, but it was obvious soon after Cameron started there that he had a definite preference for the kindy and so did I. He was included so well and warmly welcomed by the local children and families.

It was around the same time that I went to a MyTime session and met a guest speaker, a woman whose son had Down syndrome and was attending a regular high school. She was very clear about all children being able to attend their local school regardless of development, academic ability or being ‘Prep ready’. That was exactly the information I wanted to hear as Cameron wasn’t yet walking, toilet trained, he couldn’t communicate well and had some challenging behaviours. This parent talked about her son’s ordinary life and his inclusion at school.

“ THE BOYS HAVE BENEFITED ENORMOUSLY BY THE PEER MODELLING OF THEIR CLASSMATES, THE FRIENDSHIPS, BEING IMMERSSED IN THE LIFE OF THE SCHOOL, AND THE PRIDE THEY HAVE OF GOING TO THE SAME SCHOOL AS THEIR SIBLINGS. ”

Sonia Greenough

“ BEFORE ENROLLING I ATTENDED A NUMBER OF CRU WORKSHOPS, SPOKE TO OTHER PARENTS WHOSE CHILDREN WERE AT THEIR LOCAL SCHOOL AND FELT I WAS EQUIPPED WITH THE INFORMATION I NEEDED ”

Sonia Greenough

While that was what I wanted for Cam, and he was already attending his local kindy, the advice that I was being given from everyone else certainly didn't sound like he had a right to the life this parent spoke of, and that he belonged somewhere else. My youngest son, Nathan, was diagnosed with Autism soon after. It wasn't immediately all clear how inclusion would happen, but it was powerful to have someone giving permission to imagine and pursue an inclusive education, to know it was Cam's right and that it would benefit him and indeed the whole school. Not that long after, we left the ECDP and Cameron's Inclusive Education began.

After choosing to delay Cam's enrolment to school to do a second year of kindy, he started Prep where 2 of his sisters were in Year 4 and 7 there. Before enrolling I attended a number of CRU workshops, spoke to other parents whose children were at their local school and felt I was equipped with the information I needed.

The first few steps to enrol weren't as easy as I'd thought or hoped. On leaving the ECDP, they wanted a meeting and expressed concern with my decision. The woman in the office at the Primary School told me that I'd have to enrol him at the Special School (I then spoke directly with the Deputy Principal who was more aware they could not block the enrolment).

At the Enrolment Interview there was a new Deputy who said that that the school couldn't support him to attend. At every step, we kept facing roadblocks to our desire for an inclusive education. Once we met with the Special Education teacher, the support that was going to be provided was more transparent to us, and the processes for including Cam into Prep started to be put in place. There certainly have been many other hiccups along the way, inappropriate things said about my son, many more meetings than I ever expected and even being given the enrolment forms to the Special School at the end of Prep. It is exhausting at times to have your child's welcome at the school feel so conditional.

There have been staff who accept us being there and positive about it and others who weren't. The families and children in our local community have all been very welcoming and friendly and I couldn't be happier with my decision. Being embraced by that school community as a whole is what makes inclusion so worthwhile. Enrolling Nathan then was a no brainer, even though that has also come with a new set of challenges due to different support needs specific to him. Honestly, some of the teachers have been amazing, open and creative in their efforts to meet the different and sometimes difficult needs of both boys, always addressing issues positively. I need to be my sons' voice and to speak up at times when practice falls short, even when that will be unwelcome. Perhaps because of having double the advocacy load – and 7 children all together – it can be tough.



While there is a lot to celebrate about inclusive education, I find I do need to be vigilant because there can be the tendency to fall back into habits of grouping kids with disability together or seeing their place as with an adult, not with their peers.

The boys have benefited enormously by the peer modelling of their classmates, the friendships, being immersed in the life of the school (assemblies, discos, sports days, grandparent's day, book week, excursions, camps and so much more), and the pride they have of going to the same school as their siblings. Despite all the challenges that arise when you need to advocate for two children with disability, there is something that just feels right about both my youngest boys being at the same school as their siblings and following in a family tradition – and they are very much part of our local community and networks through school. They have had the ordinary school experiences of plays at the park and playground after schools and are known by so many more people than if they had been sent to somewhere special and distant.

Our most recent highlight has been Cam going on his Year 6 camp which went amazingly well. It was a significant achievement that took a lot of planning to make successful, but it is one that memories are built upon. We're about to embark on our next journey into High School.

Already I'm feeling some uneasiness about the conversations I might need to have about Cam's Inclusion but one thing I'm very clear about is that my family and I will never accept the boys being in a segregated setting. Not only do they have the right to Inclusion, they deserve it.

“ OUR MOST RECENT HIGHLIGHT HAS BEEN CAM GOING ON HIS YEAR 6 CAMP WHICH WENT AMAZINGLY WELL. ”

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“ HONESTLY, SOME OF THE TEACHERS HAVE BEEN AMAZING, OPEN AND CREATIVE IN THEIR EFFORTS TO MEET THE DIFFERENT AND SOMETIMES DIFFICULT NEEDS OF BOTH BOYS. ”

Sonia Greenough





“ SHE IS NOT JUST THE
“CHILD WITH A DISABILITY”
IN THE CLASS.
SHE IS A RESPECTED INDIVIDUAL
AND VALUED MEMBER
OF THE SCHOOL. ”

Nicole Fehr

Get Rid of Brick Houses

BY NICOLE FEHR



Nicole is a Chartered Accountant and mother of two children in Townsville, North Queensland. She was born and raised in Canada but has called Australia home since 2008. She has been actively involved and passionate in supporting other families with school aged children with disabilities with the goal of inclusion in education and the community. She loves finding the humour in everything, including raising a child with a disability.

“ ONE BIT OF ADVICE ...
IS TO MEMORISE A FEW
LINES FROM RELEVANT
LEGISLATION. KEEP THEM
HANDY IN CASE YOU HIT
A ROADBLOCK ”

Nicole Fehr

Growing up in a small town in the middle of Canada in the 1980s did not allow for much opportunity for inclusion. The people who had disabilities were in a group home, located in an old brick house on the edge of town. You would periodically see them around town, often in their group with a few carers. The behaviors of these “different” people appeared unusual to me and I would often feel scared or uncomfortable around them.

Fast forward 30 years. After moving to Australia and getting married, I gave birth to my first child. A beautiful little girl. And then the doctor said “I think she may have Down syndrome”. Those words haunted me. All I could picture was my beautiful daughter now being marched up town with her “peers”, while everyone else kept their distance. I cried. I mourned. And then I read. I read everything I could get my hands on about Down syndrome.

I read medical books, therapy books and inspirational books about Down syndrome. Once I felt comfortable leaving the house, I would take my daughter out and gauge people’s reactions to the little face with the tiny nose and slanted almond shaped eyes. So many stares. I could tell that maybe society had not changed in the past thirty years.

I signed up for every course, therapy and support group I could. Once the time came to decide on a school to send Cassidy, I had no idea where to start.

I didn’t want to send her to a special school, as I felt that it would direct her to the old brick house on the edge of town. I enrolled her in a small State school with a high proportion of children with additional needs. Something just didn’t feel right. What if she got “grouped” with the other children with additional needs? Is that any better? I went to an information night at another small State school that a friend had mentioned. At this information night, I spoke to the Principal and Head of Curriculum about my daughter. They were genuinely excited about the possibility of her attending this little school, even though they had no current or previous students with Down syndrome attend. It felt right.

After the enrolment, I asked the school if we could begin the transition to Prep. They agreed to send out Cassidy's upcoming Prep teacher and teacher aide to her ECDP school (Early Childhood Development Program) to observe her in class and get tips from the teacher there. They had a chair made to replicate the one she sat in at ECDP to be used in Prep. Once the school year started, I realised that her teacher was not just "including" Cassidy in her class, but she was changing the entire class to suit everyone. She had taken it upon herself to attend a Makaton signing course and would teach her class some of the basic signs to use. As Cassidy already used the signs, she was at an advantage.

Over the years, Cassidy has forced others to adjust their expectations. She is not just the "child with a disability" in the class. She is a respected individual and valued member of the school. She has also been the recipient of two academic awards along the way.

Over the last six years, I have learned a lot about inclusion. I have also learned a lot about how challenging it can be to implement. However, if you get the support you need, you can begin to achieve it.

The support that I initially sought was the support of the school staff. I would take any opportunity I could to have a little chat about how Cassidy is doing, how she is fitting in to the classroom, interacting with peers and performing tasks. I would provide advice and assistance in any way I could, including being the liaison between her private therapists and the school. I would observe Cassidy in a class in which she was having "issues" to see if I could identify any causes to the behaviours as well as recommend solutions. I would stand strong in my belief that Cassidy has every right to be there and succeed. I was also willing to give and take a little when expectations were a bit far apart. We are working together as a team to support her education journey.

I was and will be very visible in the school. I am very active in the school's P&C and volunteer whenever they need help. I have gotten to know a lot of the other parents of the school and their children, and they have taken the opportunity to get to know me and Cassidy. Cassidy has so many friends - genuine friends not "carer" friends - that it is often difficult to get her to leave school at the end of the day. These friends show her the respect and friendship that any other student would receive. In my opinion, that is one of the ultimate goals of inclusion.



“ LET OTHERS KNOW YOUR IDEAS FOR THE FUTURE OF YOUR CHILD. OTHER PARENTS WILL REALISE THAT YOUR VISION FOR YOUR CHILD IS NOT UNLIKE THEIRS. ”

Nicole Fehr



I understand how important the curriculum is, but I am not convinced it is a one size fits all concept. Regardless of medical diagnosis, all children have a different range of abilities. I believe the curriculum and how it is presented by the professionals should reflect that.

One bit of advice that I would like to share is to memorise a few lines from relevant legislation. Keep them handy in case you hit a roadblock. I have had to use the phrase "please provide me with the reasonable and necessary adjustments that you will be implementing so that my daughter can access the curriculum and participate in education on the same basis as her peers". A statement like this contains so many key words that Principals would not expect anyone to know. It shows that you are aware of your child's rights when it comes to education. Even if you do not have the time or understanding to read through all the relevant legislation, a few key words will help.

It has also proven to be very beneficial to keep in touch with other parents of children with disabilities navigating inclusion. If possible, meet up and discuss your children, the classrooms and the attitudes of the school. Get in touch with Inclusion Coaches in the Department of Education if possible. Support one another in school meetings.

I was asked to attend a meeting with a family regarding how the school was going to support their son with autism. They had previously left these meetings angry and confused. By just being there, without the need to actively participate, the tables were even, and the atmosphere of the meeting changed. The parents were so pleased with the outcome. There is power in numbers.

Let others know your ideas for the future of your child. Other parents will realize that your vision for your child is not unlike theirs. This will allow them to see that your child is like any other and deserves to be included as well. I have had nearly every teacher Cassidy has had tell me that Cassidy has taught the class (and the teacher) more than the teacher ever could.

Allow your child to be a teacher. By pursuing inclusion in schools, you will help create an inclusive society, and get rid of the old brick houses.

These brick houses don't benefit anyone.

“ THESE FRIENDS SHOW HER THE RESPECT AND FRIENDSHIP THAT ANY OTHER STUDENT WOULD RECEIVE. IN MY OPINION, THAT IS ONE OF THE ULTIMATE GOALS OF INCLUSION. ”

Nicole Fehr

I see him smile there everyday

BY NICOLE GREEN

I am Nicole, a married mother with one child called James* who has speech and language delays and learning difficulties. He is a happy boy who has always loved books since he was a small child, even though it has taken him quite a few years to be able to read them. James enjoys listening to music and playing in the great outdoors, especially at the beach in summer.*

When James was younger, he attended a regular kindergarten like any other child his age and an Early Childhood Development Program for children with additional needs. Both settings were very helpful to him in his early years of learning.

As it got closer to him starting school, I was asked by many parents where I would send him. As James does not have any siblings, I had not navigated the educational system before. I considered many options: special school, mainstream school and even home-schooling.

When working through the options, I talked to other parents and tried to learn from their experience and insights. There was one parent who said something to me that really stuck and that was "you won't know how he will go at the local school unless you give it a try. You could always change your mind later if you feel that decision is not the right one". This comment and James' experience in the regular kindergarten, were key in helping my husband and I decide to send James to the local State school. Yes it was scary but we thought, why not give him the same opportunity as other children?

Of course the first day of school was met with some fear (from me). I wondered how James would cope in the class and how he would go with the other kids. Will they want to play with him and will he want to play with them?

What I discovered during the first year of school was that his class, and the school community, was comprised of a diverse range of children. There were children of different races and religions, other children with specific needs, children from non-English speaking backgrounds, children who liked school and children who liked sports. This school was diverse - just like our society.

Something that became evident very early on was that children in his class treated James like any other child that attended. The children he started to make connections with, greeted him when he turned up to school, were keen to play with him at lunchtime and to help him with things. Sometimes they wanted to help too much!

James has been invited to birthday parties and to playdates. Whilst we have worked hard to foster the little friendships he has made, I do think that it has been a two way street. The friendships he has made are because he connected with those children, they wanted to be friends with him too and their parents were welcoming and open minded.

“ THERE WAS ONE PARENT WHO SAID SOMETHING TO ME THAT REALLY STUCK AND THAT WAS “YOU WON'T KNOW HOW HE WILL GO AT THE LOCAL SCHOOL UNLESS YOU GIVE IT A TRY”.

Nicole Green ”

“ I HAVE WITNESSED THESE CHILDREN BEING FANTASTIC ROLE MODELS FOR JAMES – NOT JUST IN THE CLASS BUT ALSO IN THE PLAYGROUND. ”

Nicole Green

I have witnessed these children being fantastic role models for James – not just in the class but also in the playground. They have provided peer support and encouragement to help him navigate through his day. Not only has James learnt from his teachers but he has learnt from his classmates and friends. On one occasion I was taken by surprise when his teacher informed me that some of the students had encouraged him to go to lunchtime choir sessions with them and he is very happily participating. This is some of the true beauty of inclusion and the opportunities that it can open up. He has even performed, in his own way, with the choir at the school music events.

I believe that through attending the local school, James has probably taught some of his classmates and friends some patience, definitely increased their awareness of diversity, and encouraged them to improve their inclusiveness of others.

I believe that children who learn within the home and school environment to be inclusive and embrace diversity are better placed as part of our country's future workforce for the real world - where diversity is a part of everyday life.

There have been a number of aspects where James' education has been challenging for him and us. We have had a variety of experiences with different teachers. Some teachers have been very willing to go out of their way to enable James to access the curriculum but some we have found more difficult to deal with. I think this is a reflection of teachers and teaching styles, with some teachers having a style that is more innovative.

We have never been told James can't participate in something because of his needs. Generally, he has been included in most school activities reasonably well, but in some cases we have had to advocate for him to get what we thought was in his best interest. One example was when I attended a school swimming lesson and saw that James, and some other children with similar challenges to him, were separated from the class and moved to another area of the pool under supervision of an aide. I was not happy about this and was concerned that if classmates saw these children being treated differently, then the classmates may treat the children differently too. A couple of days later, after I had taken a few breaths and thought carefully about what I was going to say, I spoke to the relevant teacher at the school. I explained that I would like James to be involved in the same lesson as the other children because that is why he was at the school. It was not just about education but also about social inclusion. In reaffirming my goal of inclusion for James instead of complaining, the teacher responded well to my approach and James was included with the other classmates.

When situations have arisen that I have not been comfortable with or happy about, I have sought advice and insights from other parents who are also navigating the inclusive school life. It has been helpful for me to be able to talk through issues with these people who have provided the support I needed. This has allowed me time to think through how I was going to approach the challenge with a fresh perspective.

The culture of the school is essential to a good student/school fit. I feel that we are part of the broader school community. I have made a conscious effort to build a good relationship with the school. I have had to advocate for James at times and I have done this through meeting with the school when required, thinking about what I was seeking from the meeting, taking my husband with me as support, and raising any concerns early in a calm and professional manner.

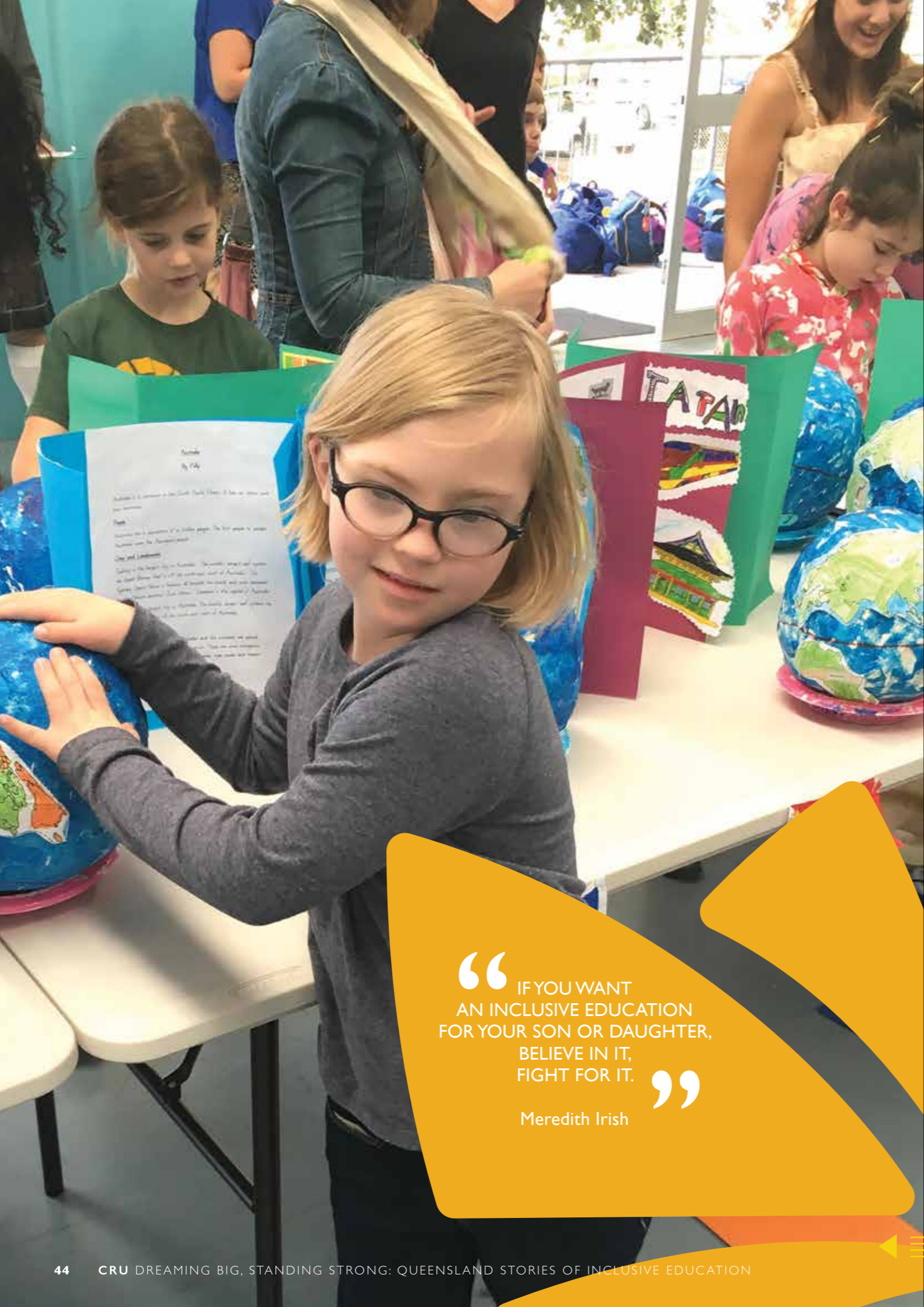
I think one of the key things I have taken away from this experience is that it is important to attend a school that you, as a family, feel you can work in partnership with. Inclusion of children in mainstream school settings is evolving. Different schools are probably at different points on this journey to others and they are all learning, just as we are.

Fast forward a few years from when he started school to now, and some of those first children James met are still his friends today. I see their kindness towards him show when, upon leaving school, James may have left his jumper in the classroom and they bring it to him. It is safe to say, the decision we made to send James to the local State school was absolutely the right decision for him. I know that, when I see him smile there everyday.

*Names have been changed for privacy reasons.

“ THIS SCHOOL WAS DIVERSE - JUST LIKE OUR SOCIETY. ”

Nicole Green ”



“ IF YOU WANT AN INCLUSIVE EDUCATION FOR YOUR SON OR DAUGHTER, BELIEVE IN IT, FIGHT FOR IT. ”
Meredith Irish

You are what is most beautiful about me

BY MEREDITH IRISH



Meredith lives in Brisbane's south and works in communication. She is married to the lovely Nick and mum to two great kids. She's chuffed to have a tribe of great friends, colleagues and inclusion advocates in her life. She is a passionate advocate for inclusive education and currently she's overthinking high school selection for both her children. She never remembers to drink her tea while it is hot. As a result she has developed a taste for lukewarm tea.

“ YOU'LL REALISE YOU HAD A HIDDEN STREET FIGHTER INSIDE OF YOU. ”

Meredith Irish

One of the things that frustrated me most after our beloved Polly was born was the constant platitudes and clichés we heard from friends, families or loved ones about having a child with a disability.

“She'll always be happy” or “God chooses special people to have a special child”. If you are reading this, I'd say you know the drill. When you have a child with a fairly obvious disability, you are always being approached in a park by a well-meaning stranger. From astoundingly stupid advice, smug superiority and disability clichés, you hear a lot of very odd stuff from strangers, friends and family members.

But in those early days, the red mist of rage would descend. I would smile politely, but in my mind that person had just revealed themselves to be a complete twit who knew nothing. In hindsight, I was probably a bit harsh.

Of course, those comments sometimes included a “where will you send her to school?” query or an anecdote about a cousin or friend-of-a-friend who had a child who went to a special school and how AMAZING it was for “those types of children”. These conversations always left me a bit rattled, but I could never figure out why.

When Polly was about three or four a woman approached me in the park one day and spoke kindly and meaningfully about her son's education. She talked about mainstreaming her son in education, and I left the conversation feeling I'd had a really authentic conversation and I needed to think about things some more. Maybe a special school wasn't inevitable for our girl.

I'd say at that point I was tired, stressed and trying to do every therapy imaginable. I was going to be the perfect mother. Except life just kept getting harder. Our daughter had some medical issues, then some more, and I was at the Early Intervention Program at a special school on the other side of town, speech therapy, physiotherapy, OT, trying still to toilet train her and feeling like a complete failure. I was worn out.

It was at this stage we enrolled our daughter in our local kindergarten program. It was pretty magic. The divine Mrs Edwards just loved Polly, and the 21 other children there in our kindy group. It was local, I could walk there, we were in our community and I finally got to breathe for a minute. We accessed inclusion support funding, which we had done at childcare, but for the first time life just felt like less of a drama. We belonged. We loved it so much we had a second year there. Mrs Edwards will probably say Polly was ready the year before. I probably needed another year there. (All up between two kids I did three years straight at kindy. I highly recommend it as food for the soul if you find the right one).

Next up was school. If you ask my husband, our daughter attending the local school was a given. It was the law and besides we'd had a good experience at kindy. I wasn't so fraught all the time, and things looked up. While intellectually I knew all the research said she would do better in a mainstream school, I still felt nervous. Would they like her? Would she blossom? How could I best protect her from the nastiness of other children if it occurred? Polly is our firstborn. It wasn't like we'd already sent other kids to school. School at that stage was still a mystery to us.

I, of course, over-researched every school. I went everywhere and met with everyone, Catholic, independent, state schools, special schools. You name it. I even researched the split placements. But a change in government policy had meant, at that time, there were no more split placements. You had to pick a camp, mainstream or special. And we decided mainstream. The mainstream decision came after an appalling visit to our local special school (not the same one we had attended the Early Intervention playgroup at years earlier). Maybe it was an off day for the staff member I met with, who knows. She was arrogant, rude and insulting to our little girl. I left wild with rage. I didn't know where Polly would go, but it would not be there. In the end we went with our local school because they were the school that genuinely wanted Polly there.

I cannot overstate the importance of a school wanting your child in the first place. Some schools, and even teachers, grow to love your child and your family, but regrettably, at least in my experience, that is rare. It's heartbreaking, and not fair and sometimes it is even against the law, but like young love, if they aren't that into you, chances are they aren't going to fall madly in love anytime soon. On reflection I think on the day of the meeting at the special school, I was reborn as an activist for inclusion. And that hasn't been a bad thing. Similarly, thinking back to the comments and platitudes people made when Polly was born, I've realised a few actually turned out to have some substance, but often not in the way they were intended.

So in that spirit, and with gracious humility in acknowledging those who have fought bigger battles than ours, I wanted to share some thoughts on how some thoughtless clichés can actually become your touchstones in building a big, rich and inclusive life for your child and your family.



1. "Oh my cousin's kid has what your kid has, you should talk to her"

Well maybe, or maybe not. Maybe you won't like that person, or their kid. But it is a fundamentally important point. You will need a tribe, and you will need different people to go to for different reasons.

Cultivate connections. Making friends is not easy, but if you think of it as cultivating a network it is easier. You'll need some true mates who understand what having a child with a disability can be like some days. How exhausting, how frustrating, how beautiful.

Find some groups of people that work for you. Some groups you won't like, or the people are weirdos and not your people, that's fine. Leave, find a different group of people, find your people. There are a gazillion groups on Facebook for inclusive education, full of tips and tricks and people's ideas. They also help you feel less alone when things are tricky.

There are people I've met at the Queensland Collective for Inclusive Education (QCIE) who can give me a spot of inclusive education advice when I send them a text. For me, that's been priceless.

2. "I couldn't do what you do"

On this they are right and wrong. They couldn't do what you do because they haven't put in the time and experience. Advocating for your child is a muscle, it gets stronger the more you do it. In time, with some wins for your child and you on the school P&C, you'll be stunned at what you can achieve.

Soon you'll be less grateful that you were offered a seat at the table, and become a bit more pushy about what you want for your child.

This will stun you, it will probably stun others around you. You'll realise you had a hidden street fighter inside of you. Some nights after a complex, exhausting school issue you'll watch your child sleep and tears will fall as you silently thank them for making you a fighter and then you will weep in great big gulps.

3. "Have you looked at a Special School, they are really great these days"

Maybe they are. Maybe they aren't, but if your gut tells you that isn't what you want for your child, back yourself. Back your kid. And if your gut is undecided, maybe read the evidence comparing outcomes.

A mainstream education hasn't been easy for any of us at times. It's been hard for our family, hard for our daughter, hard for the school, hard for our son, who attends the same school.

But it has brought riches and meaning and connection in our community. Our daughter is known and she knows her community. Isn't that what we all want in our lives, to know other people and be known?

A special school would have been hard, too, but in a different way.

People get muscled out of mainstream schools all the time. It's wrong, it's bullying and it's heartbreaking. I want desperately for it not to happen to you and your child.

But it might. I've seen it happen and mopped up the consequences with friends who moved into the 'special' pathway only to find it wasn't the land of honey and unicorns they had been promised.

Don't let yourself and your child be forced into a special school if it is not where you want to be.

I've seen Polly achieve things I never thought possible. I've seen her step up and stare down fear to achieve her goals. I've seen her miss her opportunity and be consumed with fury that she fluffed her chance.

That's the stuff we want for our children. To learn they have a place in this world and to take that place.

We know in our hearts that an inclusive education has been the right thing for Polly because it has given her those opportunities. In all their richness, in their messiness.

We are helping our girl to build a life of her choosing.

There is a wonderful line in the book *Dear Sugar* by Cheryl Strayed that I think of often, "I'll never know and neither will you of the life you don't choose... It was the ghost ship that didn't carry us."

If you want an inclusive education for your son or daughter, believe in it, fight for it. Don't stand on the shore and wave at the ghost ship of a life you secretly wanted.

Go well. Dream big. Stay strong.



“ADVOCATING FOR YOUR CHILD IS A MUSCLE, IT GETS STRONGER THE MORE YOU DO IT.”

Meredith Irish



“ TO PURSUE INCLUSION REQUIRES VIGILANCE. I HAVE FOUND THAT IT IS NOT ENOUGH TO SHARE YOUR HOPES AND VISION AND EXPECT IT TO STICK.

Julie Huysman

”

My name is Rémi. What's your name?

BY JULIE HUYSMAN



Julie is the mother of 2 boys, including her son Rémi, who is in Year 5. Julie was born in Brussels, Belgium, and migrated to Australia after completing her studies in Linguistics. Rémi and his younger brother were born in Brisbane and are being raised in a bilingual household, speaking French with their mother and English with their father. Both boys attend their local public school in inner Brisbane. Julie currently works at QPASTT as a counsellor/advocate for people from refugee backgrounds.

We chose inclusion because it seemed like the most natural thing to do. I never questioned that decision until the option of a special school was put to me by an educator at an Early Childhood Developmental Program, which Rémi was attending once a week in addition to a regular kindy program. Whichever way I looked at it, the idea of a separate education system where my son would spend 6 hours a day exclusively with children who also struggled with some aspect of their development did not make sense to me.

Peer pressure is often spoken about in terms of its negative impact on behaviour and social development. More often than not, what I have seen with my son is his emboldened spirit and sense of pride when he accomplishes a task which he was finding challenging but wanted to do because his peers were doing it. We recently cycled to school after repeated requests from Rémi, an activity which involved negotiating the busy traffic around school with his younger brother. Several kids recognised that it was Rémi on the bike and waved and greeted him with enthusiasm. At pick up time, I saw him chatting with other students on the way to the bike rack and noticed the swagger in his gait! It also looked like seeing my son ride his bike to school instantly changed something in those students' perception of him and told them that though he may be different from them in more obvious ways than other students, this does not stop him from riding his bike to school.

“ RÉMI IS VERY SOCIAL. HE IS INTERESTED TO GET TO KNOW PEOPLE AND REMEMBERS EVERYONE'S NAMES. HE CAN LIGHTEN THE MOOD INSTANTLY WITH HIS SENSE OF HUMOUR AND BRINGS OUT A PLAYFUL SIDE IN STUDENTS AND TEACHERS ALIKE. ”

Julie Huysman

The students and my son walked out of this encounter with an image of competence in their head, not of disempowerment, which is too often the case for children with a disability. These experiences have a carry-over effect. The next day, my son went to school with an extra spring in his step.

What has also worked well about attending our local school is that my son often runs into students from his school at parks and venues in our neighbourhood and this means more opportunities for building friendships. A few years ago, my son was very keen to join Cub scouts and, as it turned out, two of his school mates started to attend shortly after he joined. They became good friends, sought each other out at lunch breaks, and had several playdates. The brothers eventually had to move away but this friendship played an important role in helping Remi feel connected and having a sense of belonging at school, especially outside of class time.

Remi is very social. He is interested to get to know people and remembers everyone's names. He can lighten the mood instantly with his sense of humour and brings out a playful side in students and teachers alike. Several teachers have commented on the sense of enjoyment and satisfaction working with Rémi brings them. He has a broad range of interests, from geography, vehicles and guitar, to board games and languages. One of his previous teachers came out as a motorbike chick when she found a fellow motorbike aficionado in Rémi and they used to spend time poring over motorbike photos once Rémi had completed his work. He is also one of a handful of students at school who speak French and teachers enjoy practising their high school French with him.

Rémi is caring and also full of mischief at times. At school, he once lined up to order food at the tuckshop when he had no money and then ran away with his order. Naturally I was not pleased when I heard about this incident; however, I couldn't help also being impressed with the forward thinking and planning skills involved in pulling it off. The school did not make a big fuss and responded very well. Rémi had the opportunity to apologise and pay for the items with his own money. Reflecting back, I am grateful for the learning experience for Rémi, which came about because he is allowed the freedom to make mistakes and take responsibility for them.



Sometimes being at school is tough. There have been times when my son has not been given the same opportunities as the other students. This was often the result of the school either making the wrong assumptions of what would be best for my son, in terms of his safety or his learning, or choosing the easier option in terms of risk or behaviour management. Occasionally, my son is made fun of or treated poorly by other students, but as hurtful as these experiences can be, they have led to him developing strong coping mechanisms which generally allow him to shake off unsavoury comments or behaviours.

The fact that he is looking forward to going to school on most mornings is a good indicator of the beneficial impact of attending his local school, but what will make me continue to pursue an inclusive education for him is the fact that his place is with his peers, in the community, not outside of it, or on the periphery.

To pursue inclusion requires vigilance. I have found that it is not enough to share your hopes and vision and expect it to stick. You may start by communicating what you mean by inclusion, by painting a picture, but you will need to bring people back to that picture periodically to remind the people working with your child what inclusion looks like, for your child. What I have found useful is to have one or two core principles that I can communicate to the school to highlight what our top priorities are for Rémi and that the school can use to guide their responses, especially in more complex situations. One of our guiding principles is to keep Rémi with his peers and not use the special education room under any circumstances. The other principle is to ask the question, what would happen in a similar situation if the child did not have a disability? Then to choose what seems the most appropriate response.

Advocacy is something I do every day so it takes commitment, but you don't have to do it alone. Developing partnerships within the school may take time but is a worthwhile effort, as others will start to advocate for your child as well.

We have one more year before my son starts high school and I am nervous about finding a school that will offer Rémi a fully inclusive education. I don't know if the school we are looking for exists yet in our region but we are hoping to find a school that is welcoming of Rémi, is willing to support him to access the curriculum at year level, and wants him fully involved and contributing to the school community. The inclusive path may not be the easiest, but it has already led to many wonderful outcomes. I have no doubt that Rémi's teachers are better teachers for having him in their class. One teacher from the school's inclusion services shared with me that the reason she stayed at the school was the work she was doing to support Rémi to access the curriculum at his year level. I feel sure that the lives of the students at Rémi's next school will be enriched by having him with them, as will his.

We believe that this pathway will set Rémi up for a life rich with learning, love, friendships, work, adventure and surprises, and enable him to choose his own life direction, just like his brother.

“ WE CHOSE INCLUSION BECAUSE IT SEEMED LIKE THE MOST NATURAL THING TO DO. ”

Julie Huysman

HIGH SCHOOL



“ HE WILL NEED HIS COMMUNITY AROUND HIM TO KEEP HIM SAFE FROM THE THINGS THAT PEOPLE WITH A DISABILITY ARE MOST VULNERABLE TO, LIKE ISOLATION, LONELINESS, NEGLECT AND ABUSE. ”

Hazel Lloyd

Why Inclusion is not a Choice

BY HAZEL LLOYD



Hazel is a former map-maker Brisbane mother of 2 children, including her son Taylor who is currently in Year 7 at a mainstream high school. She has developed her knowledge about inclusive education, and how to positively advocate for this for her son, over the last few years through attendance at numerous workshops, conferences and seminars, many run by CRU. She is determined that her son will have an inclusive life, which will lead to rich and varied experiences. She is an active member of the Queensland Collective for Inclusive Education and loves travel, catching up with friends and time at the beach with family.

“ I REMEMBER THINKING, WOULDN'T IT BE GREAT TO JUST BE ABLE TO WALK TAYLOR TO THE LOCAL SCHOOL DOWN THE ROAD! ”

Hazel Lloyd

Why Inclusion?

My reasons for choosing an inclusive education for my son with a disability have changed and evolved over time. Initially our choice was kind of an accident, but as I learned more, it absolutely became about the fact that it was my son's human right to go to his local mainstream school. I learnt that he didn't have to earn his place there, he didn't have to be 'good enough' to go there, and that he had the right to appropriate supports to help him to be successful there. I also learnt that his inclusion was good for everyone involved - teachers, other students, and him. I started to see the ways that he was giving back to the school environment, and that he was not just a drain on their resources.

As my son gets older, I can see that his inclusion is ultimately about ensuring his connection to his peers through shared experiences and shared learning. These peers are who are going to be his local community, long after their school days are over. These peers are who are going to know my son, who will have a meaningful connection with him, and who I hope will ultimately help to keep him safe from possible isolation, loneliness and neglect. I NEED them to be there, when I no longer am. Inclusion is no longer a choice for our family, it is a necessity.

Choosing a School

My son started in the special education system, at an ECDP at a special school, and then doing Prep at the same school. Because we lived on the other side of town to the special school, we realised it wasn't really sustainable for our family long term for him to continue there. We were encouraged to explore all the schooling options that were available closer to us. I remember thinking, wouldn't it be great to just be able to walk Taylor to the local school down the road!

So we made an appointment and went for a visit. They were quite welcoming, but did point out that their school had lots of trip hazards, lots of upstairs classrooms, and not many (any?) other kids with a disability like my son's there.

This is the first time I remember considering whether I had the energy to advocate for Taylor in an environment where he may be the first and only child needing the type of support that he did.

We had also been told about another regular state primary school, not far away that had a long history in supporting kids with a vision impairment (one of my son's disabilities), and also about the local special school. We visited the state primary school first, where we were made to feel very welcome; we were given a long tour of the school and had a good discussion with the Head of Special Education. The staff spoke as if it was a given that Taylor was coming to the school the following year, and so we enrolled him, and he did. We never did visit the special school. Taylor's sister Maddi loved dropping her brother off at school, so when she started at the same school two years later, she felt like she knew all about it already. I remember being relieved about the fact both my kids were at the same school and that I didn't have to worry about building relationships with two lots of staff, admin, parent groups and P&Cs.

Taylor now goes to the local state high school that many of his primary school peers also go to, and which happens to have a special school right next door. After all I have learnt about Inclusion, and now can't unlearn, I don't consider the special school to be an option for Taylor. It was always a worry in the back of my mind leading up to high school that they may try to encourage us to consider the school next door, but to the school's credit, they have made us feel very welcome, and we have so far never been pressured to consider the special school as an option for Taylor. I guess the fear never truly goes away though.

Advocacy – Tips for school meetings

Over the years, while pursuing an inclusive education for Taylor, I have adopted some approaches to advocacy which mostly serve us well.

If I have requested a meeting with the school, I always have a list of things I want to cover in the meeting. This helps me both remember everything, and it helps keep the discussion focused on the things important to me. It can be all too easy for conversations to become reactive and move in a direction you were not prepared for otherwise. If appropriate, I may send this to the staff involved in advance, for if they have had a chance to consider my issues, then maybe we can get to a resolution there and then in the meeting. I always try to start any conversation with the positives, to acknowledge the things that the school is doing great, and then move on to outline the issue/s we have concerns about and why. Hopefully this leads to a valuable discussion and some kind of plan to move forward with.



“AFTER ALL I HAVE LEARNT ABOUT INCLUSION, AND NOW CAN'T UNLEARN, I DON'T CONSIDER THE SPECIAL SCHOOL TO BE AN OPTION FOR TAYLOR.”

Hazel Lloyd



“INCLUSION IS CRITICAL TO TAYLOR'S LIFE BECAUSE IT IS CREATING A FOUNDATION FOR THE FUTURE. I WANT TAYLOR TO BE POSITIVELY AND GENUINELY CONNECTED TO HIS MAINSTREAM COMMUNITY FOR THE REST OF HIS LIFE, ESPECIALLY WHEN I AM NO LONGER AROUND TO KEEP AN EYE ON HIM.”

Hazel Lloyd

I try to remember that I don't have to agree to anything in the meeting, I can say I will go away and think about the things we have discussed. If I do agree to something that I later regret, I know I can always contact the school again and explain that I have changed my mind.

If the school requests a meeting, I try to find out who will be present at the meeting and what it is they would like to discuss specifically. I will then think about what I might like to discuss with them also, to seize the opportunity, and I write it down! I always try to remember to utilise the curious approach to any challenges they may raise with me, I ask them why they think it is happening? I think it is reasonable to expect that the staff involved have reflected on the why, and if they haven't, maybe this is a good way to prompt this to happen.

For all meetings, I will usually ensure I have a support person with me, unless I am very comfortable with who and why we are meeting. A support person can be any trusted friend or family member. They are someone you can debrief with later, another pair of ears, another perspective on what was said, and someone who can possibly call a stop to the meeting on your behalf if it all becomes too much.

These strategies (and more!) were learnt over time via things like attending Inclusive Education seminars, workshops and conferences (many of them run by CRU), connecting with other parents both in person and on-line, and through trial and error. Peer support (other parents) is such an important factor in your role as an advocate - it helps sustain you, gives you ideas, information, confidence and the knowledge that you are not alone. Unfortunately advocating for your child's Inclusive Education is likely to be a marathon, not a sprint, so you will need support along the way. Hopefully there will also be times when you feel you can offer support to other parents, as that can be just as valuable as receiving it.

The rest of his life

Inclusion is critical to Taylor's life because it is creating a foundation for the future. I want Taylor to be positively and genuinely connected to his mainstream community for the rest of his life, especially when I am no longer around to keep an eye on him. I want these connections to be mutually beneficial, they should be built on fun, mutual interests, common experiences and they need to include mutual respect, care, empathy, and support that is freely given. I say freely given, not because he can't access the paid support that he will need throughout his life, but because I believe that freely given support is what is more likely to last, to be a constant, and to be the most meaningful, throughout his life. I also say mainstream, because others with a disability cannot necessarily provide the kind of support and safe-guarding that my son will need in his future.

Hopes and Dreams

My hope is that the real connections Taylor has already made, and will continue to make, during his mainstream schooling years, will mean that his community will step up and support and safe-guard him in the future. He will need his community around him to keep him safe from the things that people with a disability are most vulnerable to, like isolation, loneliness, neglect and abuse. But it isn't all about what Taylor needs, in return, he makes people feel good. He makes them laugh, and maybe makes them think in ways they haven't tried before. He helps people see the joy in the little things, he helps them realise that different is not scary or hard to deal with. These are all significant contributions to other people's lives. My hope is that the children and young people Taylor grows up with see that diverse and inclusive societies are good for everyone.



“ WE ENROLLED MILLIE IN A REGULAR SCHOOL BECAUSE WE KNEW THE RESEARCH THAT THE OUTCOMES WERE ALWAYS BETTER SOCIALLY, ACADEMICALLY AND IN EVERY OTHER WAY FOR CHILDREN WITH DOWN SYNDROME WHO ATTENDED MAINSTREAM EDUCATION. ”

Matt Harvey and Lindie Brengman

New Vision, New Friends, New Voice

BY MATT HARVEY AND LINDIE BRENGMAN



Lindie Brengman and Matt Harvey are parents of four children who have all attended school together. Matt's personal experience with his brother, who attended segregated education, led him to become an advocate for an included life for his own daughter. Matt is a local GP with an interest in engaging with health professionals and politicians to improve practice for people with disability and their families. Lindie is an Occupational Therapist who now works at CRU as a consultant for the Families for Inclusive Education Project. Both have been actively involved in the Queensland Collective for Inclusive Education (QCIE). Their daughter, Millie, is now 16 and in Year 10 at school.

This contribution is an edited version of a presentation given at CRU's 30 Year Celebration Events: Inspiring, Connecting, Acting for Change 3 events to mark 3 decades held in Brisbane in October 2018

“ MILLIE HAS GROWN IN CONFIDENCE, SHE KNOWS SHE IS LOVED FOR WHO SHE IS AND WHAT SHE BRINGS TO THE COMMUNITY. ”

Matt Harvey & Lindie Brengman

We enrolled Millie in a regular school because we knew the research that the outcomes were always better socially, academically and in every other way for children with Down syndrome who attended mainstream education. We were shocked, like many parents, at some of the questions and conversations that we experienced leading up to enrolment. But we thought that once we got over that hurdle, just having her in the school, with our combined expertise and the suite of medical and allied health contacts we had, it would all just, well, happen. We could not have been less prepared or more ignorant!!

Millie began to experience anxiety in year 3, by year 4 she began speaking less and less to anyone other than us, and she was diagnosed with selective mutism at the beginning of year 5, 2015. Accompanying this was dreadful panic attacks, huge highs and lows of emotion, and of course, associated "behavior", and these experiences were not exclusive to Millie. The adults around this little girl struggling to 'fit' were swinging between frustration, anger at each other, anger at ourselves, guilt, feeling completely out of our depth, educationalists and health professionals alike. And then someone suggested to me that she was in the "wrong place". And I had no answer other than my gut feeling that she belonged in this school, with her siblings and her friends. That was the end of May 2015. A couple of weeks later I saw an advertisement for CRU's live in-Family Leadership workshop: "A weekend to learn, dream, celebrate and connect". One presenter was a Canberra parent who promised to share how to have your child physically included, academically engaged and socially valued.

“...MILLIE WOULD DESCRIBE HERSELF AS KIND, DETERMINED, A LOYAL FRIEND...”

Matt Harvey & Lindie Brengman



We filled in the EOI form with our best sales pitch on how we should definitely be there – because the thought we could actually miss out was too horrific to contemplate – and much to our relief, we got a spot. When we arrived, we felt welcomed - and there was real coffee! We met some great families and had some quality evening beverage time with the two other families we were accommodated with. So we made contacts! The connections we made that weekend continue to this day.

A key learning we came away from the weekend with was about intentionally building a supported ordinary life. The second thing was learning from Jan Kruger, not only about her intentional strategies to include her son, Jack, in a regular school environment, but also that he had the right to be there, and should be there. That was the first time we'd heard that the school, and the other students, would benefit. Up until then we were just grateful that Millie was allowed to be at the school, and lived in constant fear of that phone call.

A big turning point was through a story a presenter Marg Ward shared with me, Lindie, during a small group exercise. Marg shared a powerful story about describing her daughter Mena to a school staff member and being challenged: "Why are you describing your daughter that way, listing her diagnoses and deficits? Your job is to tell me who she is, her strengths and her interests". It had brought Marg to tears and we realized that when Millie started school 6 years beforehand we were able to describe her positively, talk about her strengths and interests, but years of conversations about what she couldn't do had led us to a place where we were far quicker to automatically describe a list of deficits, almost as a way of 'beating others to it', a defense mechanism and a way of protecting ourselves from being hurt. And Millie had not been shielded from this. The impact this had on Millie's self-concept was horrendous – in her first psychologist session in 2015, she was completely unable to describe herself positively and it was heartbreaking. In that moment, we intentionally began to change the way we spoke about Millie, and from that weekend, we set a course in claiming our natural authority as Millie's family, the ones who love her the most.

If we think of our most pivotal moment in our 'inclusive education' journey, we both agree: Professor Suzanne Carrington! CRU held an information evening in March 2016, where Suzanne, who is a teacher academic at QUT, spoke about 'Building Partnerships with School to Support your Child's Inclusion'. The first thing she covered was 'understanding the difference between integration and inclusion'. We nearly fell off our chairs – a focus on diversity instead of disability?! A recognition that everyone in the classroom has a right to be there, rather than trying to 'fit' children into the 'normal' class!... Oh my goodness it was earth shattering for us. And then, in Suzanne's presentation, came the big bombshell: It was not just the right of our daughter to be there, but it was a legally protected right. We could not believe that this 'inclusive education' thing, this thing that seemed so fair and made so much sense, was actually also expected! I know we weren't the only ones leaving that night wondering, "So why are we still having to fight?"

We continued to attend workshops and connect with other families. Alongside our own evolution in understanding inclusive education better, we both got involved in the Queensland Collective for Inclusive Education, a group of families who promote inclusive lives, support each other to keep pursuing inclusion, and work together to make inclusive schools a reality.

We have never found the work with QCIE tiring, exactly the opposite. It restores our energy because we're surrounded by amazing beautiful people who love their kids and believe in inclusion of everyone. It is actually exhausting to be around people who struggle to see our girl as a person. Being involved with QCIE and connected with advocates here, interstate and internationally, balances the power equation between parent and system. Our knowledge of what's possible is some serious power. We have asked for so much in Millie's school life that we never would have dreamed possible or thought about a few years ago, because we now exist in an 'inclusion possible' world.

Most of the time we have no way of predicting that we are pushing against the status quo until we get a surprising negative response. Can Millie do Japanese too? Can Millie have an assignment booklet that she can bring home (instead of worksheets kept at school), like all the other kids in her History class? Can Millie work in a group of peers too, instead of being paired with the Teacher Aide? Can Millie have a criteria sheet too? – She wants to see how she can get an A.

Through QCIE, we have attended Parliamentary Forums in Canberra, presented to student teachers and educational professionals, and at other conferences, been part of political lobbying, and developed resources for families and teachers, and run coffee and chat peer support sessions. While this work has an impact, nothing inspires what is possible like our children being in their regular schools, where they are supposed to be. We are now in contact with a Mum who is pursuing an inclusive education for her son because she watched Millie walk across the stage 2 years ago to shake the Principal's hand and join the graduating year 6 class. She said she turned to her husband and said, "See, it is possible!" We didn't know each other then, but now she attends the QCIE Peer Support coffee mornings, we are in regular contact, and she inspires us with her determination and belief in her child's right to be included.

Since our first contact with CRU at that Family Leadership Weekend, Millie has grown in confidence, she knows she is loved for who she is and what she brings to the community. After not speaking to people other than loved ones for 3 years, to everyone's stunned amazement she began speaking last year, everywhere and to everyone. She has become a strong advocate for herself, backed by parents who tell her through actions and words that she has the right to the same as everyone else. Earlier this year, her English class was given a persuasive speech on how teenagers can be brave. Presumably because it was considered easier, she was given a different topic, pizza. She was a brave enough teenager to ask her teacher to do the task on being brave.

She wrote it and presented it, and bounded out of school that afternoon with an enormous sense of pride. If asked today, Millie would describe herself as kind, determined, a loyal friend; she is responsible, has a keen eye for putting together 1000 piece puzzles, and will giggle with glee as she completely wipes you out in a game of UNO. Millie signed herself up for the school's social running club, the tennis club, and trained as part of the year 8 volleyball team even though after 3 minutes of game time she found balls flying at her head wasn't for her. She wants to be a scientist, but has found she also loves ICT, and has a keen interest in robotics.

At the end of this story of change, that without CRU would never have happened, there is our daughter who has found belief in herself, and a vision for her future. We are strengthened to combat the low expectations, and so is she. Thank you to all our new friends who have helped us dream big, to find our new vision, and who helped Millie find her voice!



“NOTHING INSPIRES WHAT IS POSSIBLE LIKE OUR CHILDREN BEING IN THEIR REGULAR SCHOOLS, WHERE THEY ARE SUPPOSED TO BE.”

Matt Harvey & Lindie Brengman

“ WE DECIDED TO APPROACH OUR LOCAL STATE SCHOOL ABOUT HIM ENROLLING INTO GRADE 5 FULLTIME. THIS DECISION WAS DRIVEN BY LUKE’S DESIRE TO BE WITH HIS PEERS IN A STIMULATING NOISY ENVIRONMENT ... ”

Ann O’Brien

Luke’s Story: The Getting of Wisdom, Courage and Hope?

BY ANN O’BRIEN



“ WONDERFUL THINGS ARE HAPPENING AT SCHOOL FOR LUKE. ”

Ann O’Brien

Ann O’Brien is the mother of 3 sons and lives in Brisbane’s inner south. She is a teacher, loves to run, and passionate about raising great boys. Her eldest son Luke has Cerebral palsy, is non-verbal, and visually impaired. He is now 21 years old. Luke completed most of his schooling in mainstream education. Luke now spends time following his passions: his love of music and hanging out with friends and family.

This contribution was originally published in CRUcial Times edition 46 in 2014. It was a written version of a presentation given at Forum in September 2013 celebrating 25 Years of CRU. During the presentation, with the assistance of his father, Dan, and his teacher’s aide, Darrel, Luke changed the slides using a switch connected to the computer.

This is Luke’s story. It is also about the getting of wisdom, courage and hope (for his parents). What you will hear about today are aspects of Luke’s life that reflect what we believe have helped to shape his life and ours as a family. You might call them guiding principles or themes.

Luke and I put this presentation together using his Pragmatic Organisation Dynamic Display (PODD) book - this provides us with key words that allow us to work out what Luke wants to say. Luke communicates by answering yes or no to questions by lifting his hand or head for yes and keeping still for no. During this process Luke demonstrates great patience and tolerance as he strives to communicate with us. One of the teacher aides recently said to me how she admires a Luke’s ability to show forgiveness for those of us who constantly ignore his potential, talk over him or not wait for the answer.

There is no doubt that Luke has much to offer to those who take the time to get to know him and listen to what he is telling them. As you listen to his story it is my hope that you will capture a glimpse of an inspirational young man who we and our family and friends are very proud to call son, brother, nephew, grandson and friend.

Luke is the eldest of 3 boys. He is almost 15, Isaac is 12 and Nathan is 10. Dan and I are very biased but we know we have 3 fabulous boys who constantly bring us joy, love and the usual frustrations, exhaustion and heartache that go with raising a family.

As a family we aim to live an ordinary life and to pursue everyday activities. We plan holidays, go on weekend outings, attend sporting events and are involved with the schools our boys attend. We also spend days and weeks in hospital, many hours at appointments. We try to live a normal life ... whatever that means.

“ WE KNEW MANY WOULD NOT UNDERSTAND OUR DESIRE FOR LUKE TO BE PART OF OUR LOCAL SCHOOL ... ”

Ann O’Brien



Luke has many professionals in his life: therapists, medical staff, teachers, teacher aides to name but a few and each play a role in his life. We appreciate their input and their expertise but at the same time we exercise our rights as parents and advocates when making big decisions. This has been something we have had to learn to do, and it hasn't always been easy. We are fortunate now to have a few professionals in our life who know us well and respect our opinion. There are of course times when we are not heard and we have to fight for what we believe is in his best interest.

We try to stay clear of the medical world and the world of disability because they tend to focus on what is wrong rather than right. Life does get really tough. Luke has extended periods of ill health, often with hospital admissions where Dan and I live between the hospital, home and work. Life has taught us that this will eventually pass and we do the best we can at the time.

Courage

If I am to reflect on the place of courage in our lives, there are a number of significant decisions that we made that required us to take a risk. My husband and I, and our other boys, are called to be our sons ally; we are his voice; we hope we speak truthfully his hopes, desires, likes and dislikes. We hope also that we listen to what he wants his life to be like.

In 2007 we decided to approach our local state school about him enrolling into grade 5 fulltime. This decision was driven by Luke's desire to be with his peers in a stimulating noisy environment. He was already going to our local school to attend philosophy and he was telling us through his actions where he wanted to be - in a regular school, with his peers, not in the special school.

It was not an easy decision. We knew many would not understand our desire for Luke to be part of our local school where his brothers attend, nor would they appreciate that he had much to offer to other children. We put ourselves on the line and then couldn't back down until we achieved what we had set out to do. I can remember driving away from meetings fighting back tears while my husband was busy remembering every swear word he knew. After much discussion, disagreement and frustration approval was given and Luke began grade 5 in 2009.

Luke is now in grade 9 at our local high school. He enjoys school especially music and socializing at lunchtime. He is not so fond of maths. How do we know this? He often goes to sleep!

Wonderful things are happening at school for Luke. There is a cohort of students who have recently come together with the assistance of a teacher and have formed a circle of friends. These are students who have formed a connection with Luke over the last 18 months and now want to be more involved in his life. This group of students met to discuss how they could contribute to Luke's day. Suggestions included: reading the newspaper in the morning to Luke, taking Luke to the admin block at the end of the day, taking him to and from class and to lunch.

The school population is made of students from many different countries. Luke's presence at school does not faze them as many come from cultures which have a very strong sense of community and an understanding that all people contribute in different ways. If you were to watch Luke in that environment you would gain very quickly an understanding of what it means to him to be there in amongst the noise and life of a high school.

“ THE MOST IMPORTANT LESSON LEARNT WAS ABOUT THE IMPORTANCE OF TAKING A RISK AND FOLLOWING YOUR DREAMS. ”

Ann O'Brien



“ HE ENJOYS SCHOOL ESPECIALLY MUSIC AND SOCIALISING AT LUNCHTIME. ”
Ann O'Brien

While planning for Luke's inclusion into our local state primary school we also decided to take 6 months to travel around Australia. My husband and I planned carefully and ensured that we had thought through what we would need to keep Luke safe, given he has, at times, significant health issues. We were aware of the risks we were taking but decided that the experience and the benefits would far outweigh any of the risks. The reality was that we would deal with whatever life threw at us at the time. Our trip was a wonderful time together. We saw only some of what this beautiful country has to offer, but memories of those days keep us going when times are difficult. Luke experienced all we did, often on Dan's back as we climbed mountains and explored gorges.

The most important lesson learnt was about the importance of taking a risk and following your dreams. Had our son's health deteriorated or the trip been too exhausting we would have rethought our plans or if necessary come home. If we had, however, allowed those potential risks to overwhelm us, what wonderful experiences we would have missed out on.

Luke demonstrates courage most days of his life. Wanting to be out there... dealing with the injustices of others, living with illness and hospitalization on a regular basis.

A vision for Luke's life

When we talk about a vision for Luke's life we think of the ordinary: schooling, friends and all that comes with it, and therefore it is vital then that we listen to Luke. His schooling was a good example of this; he was telling us through his behaviour that he wanted a mainstream education and we could not ignore this. It is vital that we consider what he loves to do, what his strengths are and in turn that we believe he has much to offer to those he meets.

Family life comes with challenges but when there is a member with a disability it is all the more challenging. Making family work when there is a child with a disability is a conscious choice. If we spend all our time wishing life was different then we end up missing the beauty and the joy of what we have.

This certainly applies to our life with Luke. This is our son and he has much to offer, if we take the time to listen and learn.

The future....

We need to ask ourselves a number of questions about what we want Luke's life to become. What are we doing to plan for Luke's future? What does Luke want? What do we think would be good for him?

We need to consider Luke moving out of home into his own place with support. To help make all of this happen we also need to think about inviting family and friends to be a part of a circle of support. We need to have support of the village to raise our children. We need lots of heads and hearts together to dream what could be possible for Luke's life. We need to ensure that Luke will be safe by sharing what we know about him, with those who are prepared to be around for a long time. There will also be a wider support network to be there when times are tough due to ill health or hospitalisation. Luke's life will be so much richer by forming closer relationships with those who care about him.

If we look back on our life with Luke there were times of planning, living, reviewing, thriving and barely surviving. We look at his life in stages and never think too far ahead... It's too hard. We do think, and are aware that, there are times when we need to consciously plan and begin the process that will bring those plans to fruition.

What have we learnt?

Life is full of ups and downs and we need to appreciate and remember the easier times. We have learnt to respect the ebb and flow of life and to choose our battles. We don't have or need all the answers now, we just need to keep asking the questions. We are still learning about Luke and about ourselves. Each person is unique and one size does not fit all.

We do not know if our son has a good life - that's for him to say... but we do strive to do what we think is in his best interest. We are listening and learning from Luke.



VOICES FROM EDUCATION



“ ALL CHILDREN ARE SEEN AS WORTHWHILE INDIVIDUALS WHOSE IDEAS AND CONTRIBUTIONS TO THE GROUP ARE VALUED AND DIFFERENCES BETWEEN ALL INDIVIDUALS ARE A SOURCE OF INTEREST AND CELEBRATION. ”

Desley Jones

Creating a Caring Community of Learners...For All

BY DESLEY JONES



Desley Jones has worked as the full-time Teacher/Director of Ballymore Kindy since 2000 and has built up a wonderful reputation for Ballymore Kindy amongst local families. Desley has a Diploma of Teaching (Early Childhood), a Bachelor of Education and an Honours Degree in Psychology. Desley also frequently writes articles and presents workshops for early childhood teachers and educators. In 2011, Desley was the recipient of a 2011 NeITA, National Excellence in Teaching Award, which honours exemplary teachers in Australian schools and early childhood centres. www.neita.com.au.

After almost 40 years of teaching, and as I near the end of my career, I can reflect that working with children with diverse needs has provided some of the most satisfying and challenging experiences of my working life. It has been a privilege to play a small part in these children's education journeys and in the lives of their families, and it has been more than evident that the inclusion of children with diverse needs has contributed to the life education of everyone involved at our centre – children, families and staff.

Parents need to be the chief advocates for their children and when your child has needs that diverge from what might be poorly termed “the norm”, the need to advocate for them is stronger. Over the years, the overwhelming message that I have taken from parents of children with diverse needs is that they wish for their child to experience connections with others, to be a member of a group, to have opportunity to play and learn, and to be valued and respected for who they are.

In 1999, I attended a keynote conference address by Dr Jillian Rodd, an educational psychologist. Jillian spoke about creating caring learning communities. She said that these caring learning communities required 5 core elements: a clear routine, clear communication, problem solving in non-violent ways, engagement in personally relevant experiences (not just time fillers), and clear expectations for behaviour.

Jillian's approach resonated with my own long term beliefs about empathy in teaching, and my commitment to using make believe play as an effective teaching and learning tool for children aged 3 to 5. This professional development experience helped me to articulate my own framework for teaching with a focus on building positive relationships. This framework is titled *Creating a Caring Community of Learners* and has formed the basis of work with ALL children at my centre since approximately 2013.

Relationships are integral to children's learning because when relationships are secure and supportive, children feel safe to explore and engage in a range of experiences. Learning is a social experience and all children learn through social experiences such as conversations and play and we know relationships are complex. Focussing on relationships encourages deep level learning such as understanding other perspectives, complex problem solving, action and reaction.

This framework incorporates six elements (rather than five) which inform all teaching decisions that are made for individuals and groups at our centre. These elements are:-

1. **Respect and empathy** (*the core of relationships*) – acknowledging children's feelings and experiences is the starting point for intentional teaching.
2. **A supportive base** (*the chaos and the calm*) - the physical, social, emotional and psychological environment supports children to face challenges in the group setting and beyond.
3. **Self regulation** (*care for self and care for others*) - helping children to recognise, understand and manage emotions and behaviour.
4. **A sense of agency** (*finding meaning in children's play*) – a “strengths based” view of young children, using make believe play to give children a sense of worth and competence, and to develop respect for themselves and others, together with a range of skills.
5. **Problem solving** (*empowering children*) - problem solving, in all areas of the curriculum, enhances emotional and social wellbeing, as well as thinking.
6. **Communication** (*caring talking and caring listening*) - considers the complexities of communication to help children develop a consciousness of others and to be respectful communicators.

“ PARENTS NEED TO BE THE CHIEF ADVOCATES FOR THEIR CHILDREN. ”

Desley Jones

My experiences have included working with children with autism, Down syndrome, Speech and Language Disorders, Epilepsy, Cerebral Palsy and more.

Philosophically my staff and I have consistently considered that:

- All children are considered unique with diverse needs, interests, abilities, ways of learning, background experiences and more.
- We want all children (regardless of individual needs) to feel authentically accepted and valued **AS THEY ARE** while assisted to build foundations for further learning and development.
- Efforts are made to avoid giving a message which says that a child needs to be changed or improved – we feel this is damaging for a child's sense of belonging and personal worth.
- Kindergarten staff are uniquely positioned to provide a quality early education program based on building positive relationships with, and between children.
- The use of make believe play allows for the development of skills in such a way that these skills have meaning for the child, are contextualised and transferable into further situations.
- It is essential that all children feel a genuine sense of belonging to our community (the kindy group). All children are seen as worthwhile individuals whose ideas and contributions to the group are valued and differences between all individuals are a source of interest and celebration.
- Every child is entitled to experience the rich experience of childhood, and to an education that has its basis in social play and connection with peers.

We actively work to build respect for all children. Individual interests direct the curriculum for all children providing motivation and supporting children to feel capable, listened to, respected and valued. Imagine the satisfaction of a young girl with cerebral palsy as she insists on balancing on a small chair to independently fix a rubber band to a post to hold her material wall in place as she makes her "house game", or the child with sensory processing issues who displays total engagement and plays at her space game for over 30 minutes!

Such games of make believe provide meaningful reasons for children to interact and communicate with one another, and to solve problems independently or in collaboration - taking your baby to the "doctors" gives personally relevant reasons to communicate with one another, to share ideas and to build a sense of story in play. We want all our children to experience a sense of belonging, which comes through being regarded as "one of the group" and valued for who they are and for what they bring to kindy (i.e. their ideas and their play).

Our focus is on what each child CAN do (i.e. their ideas, the games they choose, their strengths) rather than focussing on what they CAN'T do. Working from a strengths based view celebrates children for who they are, while co-creating meaningful curriculum with them that will motivate and engage them in a range of experiences.

Challenges can, and do, arise when diverse needs present issues with communication, emotional control or social engagement. It is essential to support one another as a team, and all the children, in appreciating one another, in focussing on strengths, and in accessing or devising strategies that support each of us, as individuals and as members of a group.

We know that skill development can be important to parents and children and we work in collaboration with therapists when appropriate, but we are NOT therapists. Our focus remains on the principles of early childhood education and our professional knowledge and experience as teachers and educators. We believe that when skills are incorporated into the context of children's self-initiated play, they are more meaningful. Children are more likely to stretch themselves to use them, and these skills can be better carried over into different contexts. Children's self-initiated activities result in a greater depth of wellbeing and engagement, allowing aspects of skill development may be integrated into the context of children's play and into group sessions when appropriate, so that individual children do not feel "on show", "different", "isolated" or "excluded".

At Ballymore Kindy, we take seriously our commitment to providing each child a high quality early education experience. Perhaps our greatest challenge in doing this is being able to access funding to allow us to employ an additional qualified staff member to support adult interaction with, and support of, all children in the group to whatever degree each child requires. We value that some funds are made available through State Government bodies, however this is often insufficient to allow us to provide the numbers of work hours required. In the case of children with medical needs, as opposed to developmental or learning disorders, we have found that no funding is available.

We are an experienced team at our centre, having worked together over many years. In this time, we have had the privilege of supporting the learning and development of many children – all of whom come with their own diverse needs. Through our own professional development, our connections with families and associated support providers, we have been able to build our professional confidence and capabilities. Most important for us, though, has been a clear articulation of our philosophical and pedagogical approach to teaching and our commitment to the value of play as an effective teaching/learning tool for ALL children.

“ WE WANT ALL OUR CHILDREN TO EXPERIENCE A SENSE OF BELONGING, WHICH COMES THROUGH BEING REGARDED “ONE OF THE GROUP” ”

Desley Jones

Inclusion matters: The Journey of Change

BY CAROLINE HAY



Caroline Hay has been working with children for over 27 years. She has been teaching at Faith Lutheran College, Redlands, for 12 years. Caroline is passionate about the way each individual child learns and has completed a variety of curriculum projects with Independent Schools Queensland and Griffith University. Caroline has also been a recipient of the 'DSQ Inspirational Teacher Award' and presented at the 'Down Syndrome Queensland Conference', and the 'Inclusive Directions for Education' Conference in Brisbane. She has a strong commitment to ensuring all students feel included within the school setting, and that they achieve with appropriate support and guidance in all aspects of learning.

My professional journey in inclusive education really began in my sixth year of teaching. While I had always catered for students' individual learning styles, I was using more of a grouped and/or segregated approach because that is how we were taught to work with children who required support. I thought it was working and it was.....for me! I thought it was working for my students too. They were progressing well and often meeting the standards or close to them.

“ I SAW MY APPROACH TO TEACHING AND LEARNING CHANGE DRAMATICALLY IN ONE SHORT YEAR. I STARTED TO SEE TEACHING THROUGH A PARENT AND CHILD'S EYES.

INCLUSION MATTERS. I WOULD LOVE FOR EDUCATORS TO VIEW ALL CHILDREN AS VALUED INDIVIDUALS WITH A UNIQUE SET OF CAPABILITIES. ”

Caroline Hay

In my eighth year of teaching, I taught my first student with Autism. He was a lovely boy that I was able to connect with easily. From an educational perspective, his learning capabilities ranged from Prep to Grade 3. His parents requested that they wanted him to learn with the class, but without the pressure to learn what the rest of the class was learning. In other words, they didn't mind if he coloured-in all day, as long as he wasn't pressured and removed from the class for intervention. They just wanted to see him happy, and being included made him happy. This was the first time that I ever considered the question – 'What is inclusion?' How was I going to include this young boy while the rest of my class worked way beyond his learning level.

I won't lie, the thought did cross my mind, 'Should he really be in a Year 6 classroom?' Other teachers posed the same question, but the more I worked with this young man, the more I wanted him with me in the classroom. It was where he belonged, and I saw the transformation of my class. I wasn't the only person he had a positive impact on. I continued teaching my class in a 'standard' way, while giving this boy different activities to keep him engaged. He was happy, the class was happy, and I was happy. He finished the year a more confident young man and his parents cried as he graduated Year 6. I think I did too. I had developed a very special bond with this young man, and I felt proud of how far he had come.

The next year came around soon enough and I was asked if I would have a child in my room with Down syndrome. The Head of School felt I was the right fit for this young girl. I agreed, but I was very nervous. I had no idea what to do or where to start. I was completely honest with her Mum on the first day and said I didn't really know what I was doing but I promised to try, and she was happy with that. Unlike the parents of my student with Autism, the parents of my student with Down syndrome were very firm in wanting their child to not only be included in every aspect of the learning in the classroom, but also to uphold high expectations. For the first time, I really had to stop and reflect on my practices. I couldn't do what I had always done, and that was to teach to the masses and withdraw this young girl for intervention.

The journey of change had begun, and it was exciting. This young lady was a part of every lesson, learning the same content as her peers in a way that was appropriate for her development, that wasn't too far removed from the students around her. I treated her just like everyone else and she responded. If I raised the bar, she raised the bar.

We had times where the wheels fell off and moderate support was required, but for the most part, this beautiful girl was flourishing because she knew her value amongst her peers. I saw my approach to teaching and learning change dramatically in one short year. I started to see teaching through a parent and child's eyes. I suppose I started thinking about my own child who was also on the spectrum. What did I want for her and how would my feelings as a parent shape who I needed to become as an inclusive teacher?

For me, at its core, Inclusion means that every child feels valued, worthy and included. It's about equitable access to all opportunities while respectfully observing the rights of every person. In the classroom environment, inclusion is about students accessing the same curriculum as their peers while being suitably supported with reasonable adjustments made alongside their classmates.

Inclusion requires a lot of initial planning and that should not be done in isolation. It takes a village to raise a child, and the most knowledgeable people in any child's life are their parents. It's essential to work with the parents, not only prior to learning, but also during the learning. Great outcomes can be achieved when all stakeholders (teachers, parents, support staff, professional health care workers) work together to achieve common goals.

I have two important guiding principles when planning for any student. The first one is start from the top and work your way down to the bottom. That is, never dumb down any of the learning because you assume the child is unable to understand or participate in the lesson as planned. Set high expectations from the beginning and adjust as you go. This requires very close observation and quick intervention to reduce any stress on the student, but it's worth it.

The second principle is 'Relationships'. Relationships are the key to all learning. Without relationships, there is no learning. All children need a relationship with the teacher. It is the very foundation to all learning. It's that simple.

We underestimate children. They are born compassionate souls and the world changes them as they grow in a society that is not always fair, pleasant or nice. In a classroom that is centred around inclusion and acceptance for all, you will see the greatest examples of love, understanding, empathy and care. The acceptance of differences is just the norm in an inclusive classroom. The teacher is the key role model here. The students follow him or her, and this can be a game changer.

As stated, my teaching practice has changed for the better since I am able to see things from the student's perspective before my own. I consider their viewpoint often. I am more compassionate and driven to see all students succeed regardless of their ability.

Having a strong commitment to inclusion, doesn't take away from the reality that there can be, and usually are, daily challenges. Challenges aren't cause for alarm though; they help everyone concerned to grow. Yes, developing the relationships needed for inclusion to work can be tricky. It can take quite a while to develop trust and understanding. You need to be patient and keep focussed on what is best for the child. You need to keep thinking and exploring how to modify tasks in a way that allows for a child to demonstrate their understanding. I like to be creative here to keep my students engaged. I spend a lot of time making sure that the task of a student with disability is as similar as possible to the task that everyone else completes.

Inclusion matters. I would love for educators to view all children as valued individuals with a unique set of capabilities. Simply put, we are all different. If we view people in this way, then the focus can be taken off the disability. It is sad when the disability becomes the focus and the focus on ability is lost. Let's just run classrooms where no one is removed, and difference is valued.

My message to my fellow teachers would be - view all students in your care as your own. How would you want your child educated? Treat them with love, care and compassion, and offer them the inclusive and equitable environment they deserve to have. Every child brings so much to the learning environment. Let's tap into that. They bring unique cultural, family and learning backgrounds, experiences and interests. When these are valued, shared and explored, students feel like they belong. When students belong and feel included in all aspects of the school community, there is an increased desire to participate, stronger feelings of worth and most definitely, a positive learning outcome.

“ LET'S JUST
RUN CLASSROOMS
WHERE NO ONE
IS REMOVED, AND
DIFFERENCE
IS VALUED. ”

Caroline Hay

Inclusive Education: None of us can remain neutral

BY LOREN SWANCUTT & BRONWYN REGUSON



Bronwyn Reguson is certified practising speech-language pathologist with over 20 years' experience working across all sectors including education, health, early intervention, private practice and university as adjunct lecturer. Bronwyn is an innovator in her field having led the transformation of speech-language therapy service delivery in North Queensland. After working as lead tutor and regional coordinator of the More Support for Students with Disabilities, she became Regional Inclusion Coach for North Queensland in 2016. She has led the Region's disability and inclusion work package designing differentiated capability development for school leaders and staff. Her passion lies in organisational transformation, coaching families and educators to collaborate to ensure all children reach their potential.



Loren Swancutt is a substantive Head of Inclusive Schooling at a government high school in North Queensland, with 11 years teaching experience across both primary and secondary school settings. She is an experienced school leader, and has successfully designed and led whole-school inclusive reform. Loren is highly regarded for her innovative work in relation to differentiated teaching practice and inclusive curriculum provisions. She has recently been seconded into Regional coaching roles, supporting Principals and school teams to advance inclusive education practices. Loren is the National Convener of SINE - the School Inclusion Network for Educators, and a doctoral candidate at the Queensland University of Technology (QUT). She is regularly invited to present on the topic of inclusive schooling across Australia.

A interview with Loren and Bronwyn –

Can tell me about your personal and professional journeys in relation to inclusive education?

LOREN

When thinking about where my passion and commitment for inclusive education started, I'm led back to my childhood experiences. I lived in a small, middle-class pocket of what was considered the wrong side of town. My parents never had any doubts or reservations about sending my siblings and me to the local public school. So, I grew up alongside kids from the surrounding area whose life circumstances and experiences were quite different to my own. They were my friends, and were an incredibly valuable part of my childhood. I was raised to not only appreciate that diversity and to be kind, but to also recognise and call out the unkind experiences which my friends had that would sometimes juxtapose with my own.

As I grew, I became increasingly aware of the marginalization experienced by those who played such an important part in my upbringing. It is a reality that has always sat uneasy within me, and has continued to drive my passion for social justice and inclusion both personally and professionally.

I entered my initial teacher education career with a determination to challenge the status quo, and to do something about the inequalities of mainstream education. I was fortunate to experience the benefits of inclusive education early in my training, and was able to forge a path that would better skill and prepare me to become a practising inclusive educator. I made a commitment to always pursue inclusive education, and although presented with many challenges and barriers across the years, I continue to stay true to leading this important work.

BRONWYN

There are some definite similarities between Loren's and my story in terms of childhood and family experiences and an innate drive for fairness and social justice. I come from a very large and diverse extended family, several of whom have lived experience of disability. As children we often didn't notice or pay much attention to the differences between us as we were all just part of the family, accepted and loved. I was an inquisitive and strong willed child and always argued for what was right over what was popular. That hasn't changed! I developed a strong sense of empathy as a child with childhood memories of standing up for others who were the target of shaming, name calling and being on the outer in

the school yard and in the classroom – it's never felt right or good to me to see people being left out or excluded or treated differently for just being themselves. My family, particularly my parents, modelled for me life values such as: walking a mile in another person's shoes, seeing a need and doing something about it, treating others how I would like to be treated and being willing to use my voice to speak up for others when and if they cannot speak for themselves. I still hold the same values today and I model them with my own family and friends every day.

My professional experience however is quite different to Loren's in that I did not start as an inclusive educator, instead I was going about my work withdrawing children from classrooms to provide the interventions at school that I thought best fit their needs. When I started to reflect on whether what I was doing was effective, I started to change my practice. My professional philosophy and practice has certainly evolved over the past 20 years. I became a speech pathologist because I love communicating and supporting others to find their voice. The many and varied professional experiences I have enjoyed have shaped my mindset and practice as an inclusive educator including:

1. working with families in a community owned child development centre, being welcomed into families' homes and having them lead family and child centered planning processes
2. learning from and with children, families and colleagues alike across varied teams and settings, being willing to hear what families and children told me did and did not work for them and learning that once we know better, we can do better
3. witnessing the slow yet steady culture shift as people's understanding of inclusive education has evolved over time from an aspiration to the deepening realisation that inclusive education is better for every one of us.

What does inclusion mean to you? What do you see as the non-negotiables in delivering inclusive education?

LOREN

Inclusion for me is not only about recognizing diversity, but truly seeing it and valuing it for the strength and beauty that it gives us as a society. It is about actively acknowledging and expecting difference, and continually grappling with and challenging the bias and prejudice that gets in the way of every one of us, without exception, having a fair go.

I often refer to inclusive education as an equation of Philosophy + Practice + Place. This signifies the non-negotiables around it being a heartfelt belief and moral imperative, in combination with quality pedagogical and instructional practices, and the condition of all students being present in the regular classroom, curriculum and broader school experience.

BRONWYN

I love Loren's mathematical equation as it's so simple and just makes sense. I think the complexity lies with the human aspects including reticence to change from what is currently comfortable for most. For a long time people thought that being present was enough to make inclusive education a reality and that special education was synonymous with inclusive education. Likewise I have seen many attempts at shifting practices to be more inclusive however the knowing and doing gap remains when time, effort and investment are not sustained in the long term. For me, the biggest gap is mindset. The non-negotiables then emerge for me as clear articulation of inclusive education as a foundation for an inclusive society, listening to the lived experiences of those who have not been included, widespread education to help people recognise unconscious bias, the social and human rights models and the recognition of the benefits that an inclusive education offers everyone. People need to be able to imagine new possibilities in order to work towards them in reality.

Collaboration with students and families is key to inclusive education – why is it so important?

LOREN

For me, some of the most powerful reminders of the importance of inclusive education have come from the students themselves. I have always sought out and championed their voices because of how much I learn from them. Their thoughts and perspectives have been incredibly insightful and motivating, and continue to stretch my thinking and shape my actions.

Student collaboration works! I think schools need to acknowledge that, and to be deliberate in finding equitable and authentic ways for it to occur.

At Thuringowa SHS, we used student voice and collaboration as a central component of shaping our vision and plan for inclusive school reform.

BRONWYN

I completely agree that student voice is critical - it is still frequently overlooked and underutilized. Often young people can imagine new possibilities and offer perspective on things that matter to them that adults may not see. If we want young people to tell us what they think and how things could be improved, we also have to have connected young people who feel their voice is heard.

The same applies to families many of whom have to become advocates for their child first and foremost. We have found that child/student centered, strength-based conversations that are solution focused and balance the interests of the student, family and the school is what works. We often assume that people know how to collaborate too which is not always the case so modelling the HOW of collaborative conversations is important.

Collaboration with colleagues is also frequently cited as a foundation for quality inclusive practice. What should that look like?

BRONWYN

Collaboration looks like people coming together, jumping into the learning pit together, trusting that the people around you will learn from you just as much as you learn from them, and that everyone is there to ensure each other's wellbeing as you share your thinking and practice. Collaboration is the bowl in which the key ingredients of quality teaching and learning for all students are mixed.

I think about collaboration as "the how" of ongoing improvement in schools and systems more broadly. It literally means to co-labour or work together on achieve something. Collaboration takes trust and time together for it to be meaningful. When we collaborate, we learn to see things from other points of view, critically reflecting on what is and is not working and learning from others' experiences so we can stop doing what we know does not work.

LOREN

Collaboration and collective efficacy is essential in education, and inclusive education as an embedded part is no exception. Schools and students are dynamic and complex, which leads me to think about a quote from Helen Keller – "alone we can do so little, together we can do so much." Collaboration not only increases our capacity to respond to the demands of inclusive practice, but urges us to imagine more. Without actively engaging in collaboration we can become restricted by our own direct experiences, and not knowing what we don't know.

In relation to inclusive education, collaboration is best served within and across school contexts, and extended to be multidisciplinary in nature. Some examples of how this can be facilitated include communities of practice, via co-planning teams, co-teaching partnerships, instructional coaching and instructional rounds. Such collaboration should occur via a whole-school approach, embedded as part of quality differentiated practice, and become increasingly specialised as required for cohorts and individual students.

Bronwyn, as a Regional Inclusion Coach, can you describe how the Department resources inclusion in your region?

We have several coaching positions that provide support and advice for regional and school leaders with a focus on positive behaviour for learning, autism, inclusion, English as an additional language/dialect and mental health amongst a range of other support personnel at Region level.

These roles support school improvement through professional learning and coaching support aimed at building capability of regional teams, school leaders and staff. I help school staff to take an appreciative, strengths based approach to improving teaching and learning for all students, working with regional leaders and principals to build shared understandings of what inclusive education is and to map out the support required for leaders to drive this critical improvement agenda with their school community.

I have designed and led the inclusion forums for school leadership teams bringing people together in a learning community style conversation about the why, what and how of inclusive school improvement. These forums have been a huge success with over 300 school and regional leaders attending over the past 2 years.

As part of our regional plan, we have had five regional heads of inclusion leading improvement for students with disability at a school level, working with the regional coaches across clusters of schools to build capability of teachers through curriculum planning and differentiation, case management and co-teaching. These roles are additional resources the department has funded to further the Every Student with Disability Succeeding Plan to ensure the systems and processes in schools are reviewed and improved through the lens of inclusive education.

The challenge in system transformation is often the pre-existing systems and mindsets that people hold on to despite the evidence base and strong examples of success that we celebrate and share. So we really need the culture change strategy identified so clearly in the Queensland Disability Review. Despite the challenges, we see the benefits of a focus which has shifted from students fitting the system to improving the educational experiences for all students, including students with disability, through high quality teaching and learning in every classroom. The inquiry approach that the Department is taking to school improvement has changed the conversation from a right/wrong dichotomy to one of identifying opportunities to improve.

“COLLABORATION NOT ONLY INCREASES OUR CAPACITY TO RESPOND TO THE DEMANDS OF INCLUSIVE PRACTICE, BUT URGES US TO IMAGINE MORE.”

Loren Swancutt



Loren, can you tell us about the Inclusion Café as an innovative initiative to resource teachers?

Whilst in a Regional position, I started the Inclusive Education Cafés as a response to the gap in professional learning on offer around inclusive education, and to support the implementation of the Department of Education's Inclusive Education Policy. The Cafés provided a unique way to connect and engage participants from across the North Queensland Region.

The Cafés have essentially been afternoon tea catch ups hosted at a school and open to State and Catholic Education schools with a focus on everyone contributing ideas and learning from each other. There is usually some focussed discussion to stimulate professional learning on a practice challenge, with chance for discussion in pairs or small groups. This allows delivery of practical solutions and responses to common questions and challenges of practice experienced in schools. The learning is designed to be contextual and collaborative, with participants able to engage in network coaching, generating potential solutions together and having opportunities for questions and open collaboration time. Over 20 Cafés were facilitated across 2018 and 2019, and they were attended by a broad range of school and regional based staff.

2020 presented an opportunity for me to redesign and expand the Café concept beyond face-to-face delivery in the North Queensland Region. The Cafés are now facilitated through the School Inclusion Network for Educators, and occur online through video conferencing platforms. Educators from right across Australia participate in the virtual Cafés which occur three times per term. The same principles and experiences of the existing Cafés are in place, but now with broader, cross-sector and system collaboration.

What else is needed to support and resource educators?

LOREN

My thoughts on this echo those that I shared at a Disability Royal Commission hearing into education. There are a range of factors that contribute to the ongoing systemic stagnation regarding the inclusion of students with disability. To help address these, I would like to see a national commitment to an inclusive education policy that upholds the right to inclusive education as it is outlined in General Comment No. 4 of the UNCRPD. At a school and teacher level, we know that confidence and capability have a big influence on decision making and practice. So I would like to see structures that support clear, appropriate and contextual professional learning and coaching that is accessible and responsive for schools. We need to demonstrate exactly what inclusive education is and looks like, and how it can be authentically achieved through school improvement and reform. We can't leave this work to chance or choice, we need to have teams of highly-skilled and experienced personnel on the ground in schools to assist in creating the conditions for scalable and sustainable change.

BRONWYN

In order for systems to change there needs to be a strong moral imperative which I believe we have. I do however think there also needs to be a renewed focus on leadership of inclusive education as sustained change only happens when leaders collectively create a vision with their team, stepping out a plan with a clear purpose, identifying the human and financial resources and the professional learning required. The investment then lies in the people we have implementing the change day to day in every classroom, school and system. My hope is also for a national commitment to inclusive education that sets the bar high in Australia and celebrates the improvement that schools are making. I think we also need to focus on partnering with families which is why I am delighted to see partnerships with community organisations emerging.

What are your hopes for the future of inclusive education?

BRONWYN

My hope is that we will stay true to what inclusive education means, unyielding in our determination for it to be a reality in our homes, schools and society more broadly. I believe that working with people wherever they're at is essential to building trusting relationships where people feel like they can have the conversations needed to challenge their thinking and their practices.

LOREN

And my hope for the future of inclusive education is that as a society none of us remain neutral. That we continue to actively work toward ending segregated educational responses and parallel systems. That we start asking where all of the students with disability in our neighbourhoods are, and make it known that they are needed and wanted in our regular education classrooms.

“MY HOPE IS THAT WE WILL STAY TRUE TO WHAT INCLUSIVE EDUCATION MEANS, UNYIELDING IN OUR DETERMINATION FOR IT TO BE A REALITY IN OUR HOMES, SCHOOLS AND SOCIETY MORE BROADLY.”

Bronwyn Reguson

Preparing teachers to be inclusive

BY SUZANNE CARRINGTON



Suzanne is a Professor and Associate Dean (Research) in the Faculty of Education, QUT Australia. Suzanne's areas of expertise are in inclusive education, ethical leadership for inclusive schools, disability, and teacher preparation for inclusive schools. She has engaged in research to inform policy and practice in Australian and international education contexts. She has published over 90 journal publications, books, book chapters and research reports. She is currently the School Program Director of the Autism CRC.

Preparing teachers to work in inclusive settings has been recognized as an important part of teacher education in Australia since the mid 1990s. I was initially appointed in 1993 at the University of New England, NSW, to write and teach the compulsory Integration subjects for primary and secondary teachers at a university in New South Wales. This work was very much focused on preparing teachers to teach students with disabilities in primary and secondary schools, as the focus moved away from special education. I have worked in QLD for the last twenty-five years, either in the university sector or in the Department of Education, supporting teachers and schools to learn about inclusion. Before talking more about what has been happening in teacher education over the years, I look back to my own experiences and consider why I have been so passionate about inclusive education.

When I was a school student, I volunteered at a local special school. This became an interest after having some family experience with disability. This interest led me to enrol in a teaching degree to study primary teaching and special education teaching at Griffith University. My first teaching position was in Roma, QLD where I was a teacher at a small special school that had two classes: the senior class and the junior class. The school was new and I remember the regional staff office had to identify students in the region who would be eligible to attend the special school. Some children had identified disabilities, and some had learning difficulties with additional behavioural challenges because they were struggling to receive the support they needed in mainstream education.

After two years in Roma, I moved to Townsville and taught children at a special school that was attached to an institution for children with severe and multiple disabilities. This was the late 80s and awareness was growing about human rights, access to education and support for all children with disabilities. After teaching in London, England, at a special school, I returned to Australia to Cairns where parent advocacy and regional educators had worked together to close the special school in 1990. I had the great opportunity of working at a secondary school and a primary school where parents, teachers, school leaders and students worked together to learn how to be inclusive. These collective experiences influenced my commitment to inclusive education. I always say that I learnt the most about inclusion from the parents of the children I taught.

Many parents gently and constructively gave me feedback, worked alongside me and my staff and helped us to reconsider our special education informed language and practice. I then went on to complete a PhD and focused on exploring how school communities can be inclusive where all children and families are welcome, supported in education and treated with respect. We now have decades of research that indicates that inclusive education leads to positive academic and social emotional outcomes for all students, with and without disabilities, so why do our teacher education courses struggle to get this message across to our teaching workforce?

The approach taken in teacher education subjects on inclusive education across Australia has varied and still varies enormously. In some universities, the academic staff who coordinate the subjects are still teaching about special education and often just rebrand their subjects with the title of inclusive education. Even worse in some universities, you will find subjects called Special Education/Inclusive Education and assume that they mean the same thing!!

What is the difference between special education and inclusive education?

There are many people in universities and in education organisations who do not understand the difference between special education and inclusive education, and do not have the knowledge and practical skills to support this expected change in developing inclusive culture, policy, and practice in schools. The underlying paradigm and understanding of disability commonly called the 'medical model' has informed special education for years and informs

deep beliefs about how difference is viewed in schools, focusing on deficit and how students are seen to be outside the norm. Completing my PhD involved wide and in-depth reading of the international literature. I understood that that my special education training was influenced by the medical model and reflected deficit-based language and thinking that influenced teaching practice. I realised that disability was just one type of difference in our society.

In an inclusive approach, drawing on the social model of disability, we do not see difference as a problem but value and respect all members (children, teachers, and parents) of the local school community. In an inclusive approach, teaching is learner focused with a flexible curriculum and pedagogy to meet students' needs. Teachers receive support from specialist teachers and allied health professionals to provide successful learning opportunities and outcomes for all children. One of the key challenges in supporting educators to move forward to a more inclusive approach to education is to understand how inclusion is different to special education.

Education leaders need to be Ethical Leaders and support staff to develop an understanding of and embrace inclusive education as a transformation of core business rather than an extension of special education. Indeed until this transformation occurs, we see that students, families and educators in the "inclusive education" area will continue to experience challenges.

Preparing Teachers to be Inclusive

Teacher preparation courses should be informed by the UNCRPD's Article 24 and General Comment No. 4 and explicitly teach the underpinning theory, legislative frameworks, policies and the range of inclusive teaching practices such as the multi-tier model of support and Universal Design for Learning. Although families may not know the detail about these inclusive teaching approaches, it may be useful for families to have a broad understanding of what teachers are expected to do in their practice to meet the expectations of being an inclusive teacher.

University subjects on inclusive education preparing new teachers should demonstrate how they meet the Australian Professional Standards for Teachers by addressing the following elements:

- Develop the ability to recognise and understand diverse student characteristics and how these affect learning.
- Demonstrate knowledge of teaching strategies responsive to strengths and needs.
- Set learning goals that provide achievable challenges for students with varying abilities.
- Differentiate teaching to meet specific learning needs of students across the full range of abilities.
- Be familiar with strategies to support full participation of students with a disability.
- Engage with parents and carers and external professionals.

Subjects on inclusive education also need to address values, particularly values of social justice and citizenship that promote equity, participation, respect for diversity, compassion, care, and entitlement. Pre-service teachers may have values that support exclusive practices that marginalise students. Therefore, to ensure that teachers are well-prepared to meet the needs of their students, it is important that our courses support critical reflection of social values and educational practices that support inclusion and challenge the ways that students and families are excluded from schools. As we work together towards a more inclusive approach to education, we consider how people around the world are both alike and different.

We all know that education can change lives for the better, but we also know that many of us have difficult and emotional memories of our own school years and the school years of family members. The ideal that education changes lives is at the forefront of my work and influences my commitment to work with families, school leaders, teachers and students to progress inclusion.

Read more about:

Ethical Leadership for Inclusive Schools:
acel.org.au/ACEL/ACELWEB/Publications/AEL/2020/2/Lead_Article_1.aspx

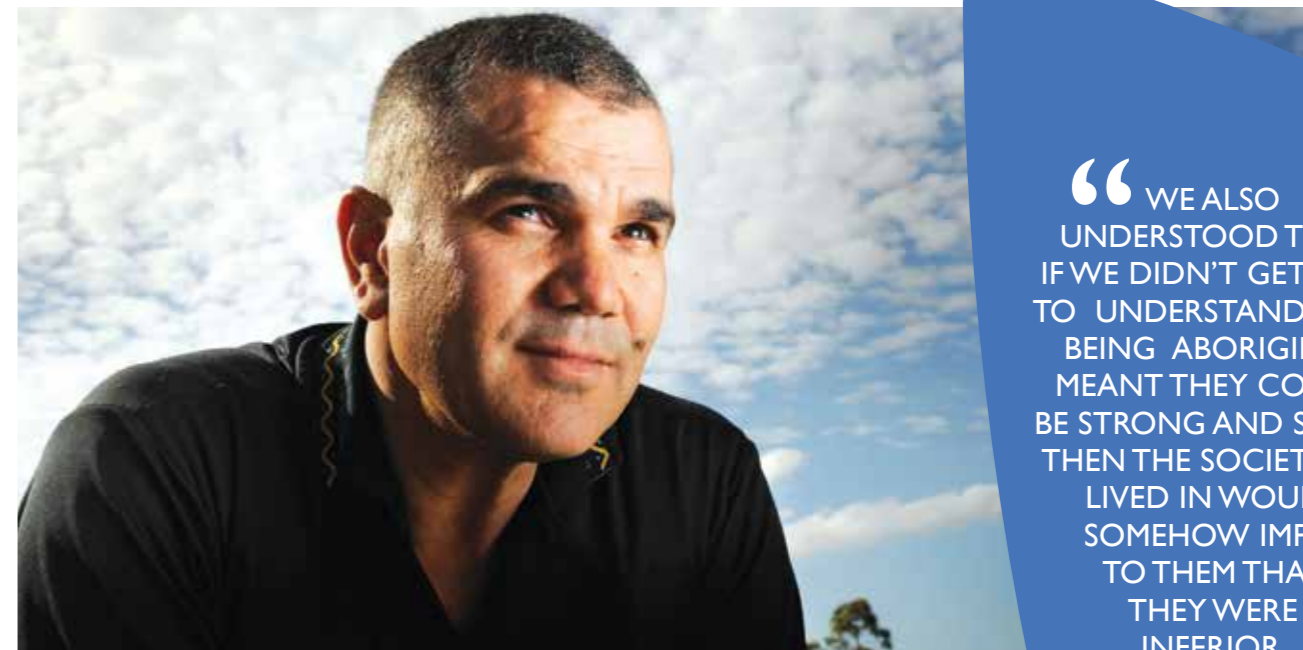
Multi-tier model of support:
school-inclusion.com/inclusion-in-action/multi-tiered-system-of-supports

Universal Design for Learning
udlguidelines.cast.org

Australian Professional Standards for Education
aitsl.edu.au/teach/standards

Stronger and Smarter

BY DR CHRIS SARRA



“ WE ALSO UNDERSTOOD THAT IF WE DIDN'T GET KIDS TO UNDERSTAND THAT BEING ABORIGINAL MEANT THEY COULD BE STRONG AND SMART, THEN THE SOCIETY WE LIVED IN WOULD SOMEHOW IMPLY TO THEM THAT THEY WERE INFERIOR. ”

Dr Chris Sarra

Chris Sarra grew up in Bundaberg as the youngest of 10 children. He became the first Aboriginal Principal of Cherbourg State School in southeast Queensland in 1998, significantly improving the educational and life outcomes of its students through a 'strong and smart' philosophy, which encouraged students to have a positive sense of cultural identity.

In 2005, he founded the Stronger Smarter Institute which works with schools and community leaders to deliver the stronger smarter approach to Indigenous students. In 2018, Dr Chris Sarra was appointed Director-General, Department of Aboriginal and Torres Strait Islander Partnerships, Queensland Government. Dr Sarra holds a Bachelor of Education, Masters of Teaching and an Executive Masters in Public Administration. His PhD thesis Strong and Smart - Towards a Pedagogy for Emancipation: Education for First Peoples was published by Routledge in 2012.

He is the recipient of many awards, including being named Queenslander of the Year in 2004, Queensland's Australian of the Year in 2010 and NAIDOC Person of the Year in 2016.

These excerpts from "Good Morning Mr. Sarra" were originally published in CRUcial Times 44 in April 2013. When Chris presented at CRU's conference in 2016, his naming of the "toxic stench of low expectations" faced by First Nations students strongly resonated with the disability sector audience. This contribution speaks to those parallel experiences and also prompts reflections on the additional barriers for First Nations students with disability.

I loved what [this lecturer, Gary MacLennan] had to say and how he said it. He is a real teacher, and one of the best. I would meet regularly with him to discuss my progress and he challenged me constantly to think deeply about what I was learning. Intellectually Gary grabbed me by the scruff of the neck in one hand, and with the other he shined a light on my entire world, forcing me to see it differently. Gary showed me the "hidden curriculum" of schooling and the "hidden agenda" of society.

On one occasion Gary urged me to do an assignment about my mother's education and contemplate what opportunities she had access to. The idea was to see how this may have enhanced or stifled my own efforts in school. It was a great idea but I wasn't sure I was ready for what it would reveal. Mum told me that she loved to read and had dreamed of being an archaeologist. It was never going to happen though, as she was only ever allowed to go to school until Year 3. When asked why, she said "I guess they just thought of us as uncivilised natives and that we weren't capable of learning".

“ I GUESS THEY JUST THOUGHT OF US AS UNCIVILISED NATIVES AND THAT WE WEREN'T CAPABLE OF LEARNING. ”
Dr Chris Sarra

This floored me to some extent, and it got me talking with my older brothers and sister about their experiences at school. Tracie said, “Remember that old hag we had in Year 2? She would make us sit at the back and say she was going to bring a bath tub in to wash these Aboriginal kids because they stink!”

As I tried to imagine what this would do to the spirit of a six or seven year old, how it would make them feel about school and the people there, things started making sense to me. I began to see aspects of my own past as I hadn't before. I saw more clearly the circumstances: I had been sold short by people with low expectations, I had sold myself short with limited expectations of who I was and what I could achieve, and I didn't know I'd done this.

I recalled the Year 11 maths teacher... hand[ing] back a test and jokingly [saying] to the class “Sarrra got seventy-five per cent! Must have been an easy test!” We all laughed, myself included. He was a good man and I really liked him. I'm sure he wasn't being malicious but in his jest he sent a message

that he didn't even know he'd sent: “I didn't really expect you to get seventy-five per cent!”

At the same time, I was receiving a negative message about myself that I didn't even know I was taking in.

In the mid-1990s Sarra describes the experience of accompanying student teachers on a visit to the school at Cherbourg.

The school was depressing, as there was rubbish everywhere, broken windows and kids ran all over the place, sometimes in highly dangerous areas. The principal and her staff would sit down with our teacher trainees and tell them why it was like this and how hard it was to teach the kids at Cherbourg, that it wasn't a normal school and that we had to have different expectations for these children because they were so different. Something was telling me that it didn't have to be this way. I knew from personal experience that if you have low expectations of people then they are most likely to deliver on that. Similarly, I knew from personal experience, that if we have high expectations, children respond to that, regardless of how impossible things might seem. Somewhere inside I was wrestling intellectually with the fact that these teachers had been here for a long time even though it seemed like they really cared for the kids. Some had been there for more than ten years. Maybe this was the best we could expect from them! If this was true then it left me with a sense of despair and hopelessness.

We heard stories about children not even getting to the end of primary school. We saw a school in chaos and completely dis-engaged from the community. In the face of all of this it was easy to look at the attendance data and student performance data and believe that the Aboriginal people of Cherbourg did not value education.

There was something paradoxical about this, particularly given our earlier conversations in the day when we met representatives of the Cherbourg Council. Men like Warren Collins, CEO of the council, and Ken Bone, the mayor, both spoke passionately about the need for good-quality education as a means to a positive future. The real question to ask, I suppose, was what existed in the school that was of any value?

At the end of our stay we got back on the bus and headed home. I was physically tired, and mentally exhausted from the immense complexity we had just encountered. Could this really be the best we could expect?

In 1998, Chris Sarra became the Principal of Cherbourg State School and started sharing with the community his vision for transforming the culture of the school.

I told them we had to create schools and classrooms that could “untrick” Aboriginal kids so that they didn't believe that being Aboriginal meant being on the bottom. We had to get them to understand that they could be high academic achievers as much as anyone else. We had to get children to feel good and positive about being Aboriginal and not conform to some kind of negative stereotype to somehow prove they were “Aboriginal”. I also said that we had to challenge teachers to see Aboriginal students more positively and with potential, we had to challenge teachers to see themselves differently and with the capacity to make a difference in the lives of their Aboriginal Students.

Sarra started to implement some changes but not everyone felt his goals were “realistic”.

It was becoming increasingly clear to me that we could lift the school, but only if we had enough people on the team believing it.

Senior teachers were trying to explain to me that it was necessary for us to adjust our expectations. When the District Office sent out a skills checklist for students in the region I was keen to see this executed across the whole school. I sent the checklist to a few teams I had established, only to have it sent back with a note attached saying, “we think this is too advanced for our children and so we are working on another checklist that is more suitable”.

It was so frustrating to see such toxic trash coming from those who were supposed to be the experienced teachers in the school. I'd ask why we had to endure failure and such endemic disengagement; the answers coming back were not good. All the things I had heard from them pointed the finger of blame at someone or something else.

Along with support from elders and the broader community, Sarra established new expectations and new opportunities for learning. He reflects on what it meant to raise expectations.

They understood that while this was about raising our status and sense of blackness, it was not about putting down white people. Understanding and embracing one's power is never about putting others down. In fact, by putting others down, we put ourselves down. We also understood that if we didn't get kids to understand that being Aboriginal meant they could be strong and smart, then the society we lived in would somehow imply to them that they were inferior. We all got that our children were much more than this.

This was about offering a way of being that was different from our sense of being in the past. It was a more honourable way of being with more integrity. It was a way of being that was more authentic and closer to the truth about who we are as Aborigines, Australia's first people who carried the blood of the oldest human existence on our planet.

Excerpts are from Good Morning Mr. Sarra by Chris Sarra (University of Queensland Press, 2012). Reprinted with permission.

“ I KNEW FROM PERSONAL EXPERIENCE THAT IF YOU HAVE LOW EXPECTATIONS OF PEOPLE THEN THEY ARE MOST LIKELY TO DELIVER ON THAT. ”

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“ SIMILARLY, I KNEW FROM PERSONAL EXPERIENCE, THAT IF WE HAVE HIGH EXPECTATIONS, CHILDREN RESPOND TO THAT, REGARDLESS OF HOW IMPOSSIBLE THINGS MIGHT SEEM. ”

Dr Chris Sarra



LOOKING BACK



“ ON ZAC'S SCHOOL FORMAL NIGHT I WAS SO WORRIED THAT HE MAY KNOW ONLY A FEW PEOPLE...

...NEXT MINUTE I HEAR “HI ZAC”, “YOU LOOK GREAT ZAC”, AND ZAC KNEW EVERYONE.

...EACH ONE TELLING ME HOW THEY KNEW ZAC FROM ENGLISH OR PE, OR FROM THE SHOPS AFTER SCHOOL. MY HEART WAS SINGING.”

Rita Schubert

“No, he is Playing in the Team!” - the wonderful journey of inclusive schooling

BY RITA SCHUBERT



“ REGULAR SCHOOL HAS BEEN THE MOST WONDERFUL EXPERIENCE... THE REGULAR PATH ISN'T PERFECT, BUT I COULD NOT BE HAPPIER WITH ALL THE OPPORTUNITIES IT OPENED UP FOR ZAC. I REALLY WANT PARENTS TO KNOW THAT THERE ARE OTHER OPTIONS THAN SPECIAL SCHOOLS! ”

Rita Schubert

Rita Schubert is an Accounts Manager and a mother of two, including her son Zac who is 18. She has worked in recruitment for 14 years. She loves to catch a live gig and spend time with friends camping. These passions have enriched family life beyond words.

Schooling is a journey and a half for any child and parent, but when you have a child with disability, it is even more so. When my son Zac finished school in 2019, I felt incredibly blessed to have chosen the path of regular school and the specific schools Zac attended. I have so many wonderful memories!!

The day Zac was born I remember a specialist saying to me he may even be able to attend mainstream school. I didn't even know there were other options. I have learnt a lot since then!

I went to a small Catholic primary school, along with twin autistic boys and a boy with Down syndrome. I had always played with them in break time. I didn't even know what autistic or Down syndrome was until I was a teenager. I saw them as my friends, no different to any of my other friends. They were my mates and my classmates saw these boys the same as me. So for me it was incomprehensible that Zac would not be included!

My older daughter had started at the local primary school. She was anaphylactic to nuts, back when no one was educated on anaphylaxis. After a year of nothing short of hell, I switched to the local Catholic school. When I met with the Principal she said I will take her but this does not guarantee sibling entry. She had never met Zac and had no idea he had Down syndrome, so you can imagine my thoughts.

I felt extremely fortunate that Zac was accepted. In the meetings with Cath Ed prior to starting, I was as open and honest as I could be. I developed a great rapport with the Principal and his teacher and we all worked together to make it work.

The community immediately accepted Zac. The Year 7 students all fought to have Zac as their buddy, and we had 12 year old girls coming to our house after school asking to play with Zac! That cohort took him under their wing and his class instantly warmed to him. Zac's speech was not the best, but the kids all understood him, even when I didn't. He quickly developed great friendships, true friendships.

When we started Grade 1, the Principal suggested a goal of being able to swim 25 metres. The school had lunch time swims, and she thought it would be great for Zac to be easily able to join in socially. But Zac was super scared of the pool. In Prep, we put in a pool and we hoped he would be more confident in his own pool. It didn't really have that effect at all! I ended up doing one on one lessons daily through the school holiday break. We invited friends over almost daily for more swim practice. And by the Grade 1 swim carnival, Zac swam 25 metres. The whole school cheered for him. I was in complete tears and so super proud.

In Prep, a mother came up to me and said my son wants Zac to join his soccer team. I initially thought, does this mother have the right Zac? Zac had extremely low tone. I didn't know what to say, replying, "well, I suppose he can do the oranges". She was "umm ... No, he is playing in the team!" That first training I didn't know what to expect. The team was made up of mates from his class and the boys had organised it all themselves. Zac was given the same time on the field as the others and never treated any differently.

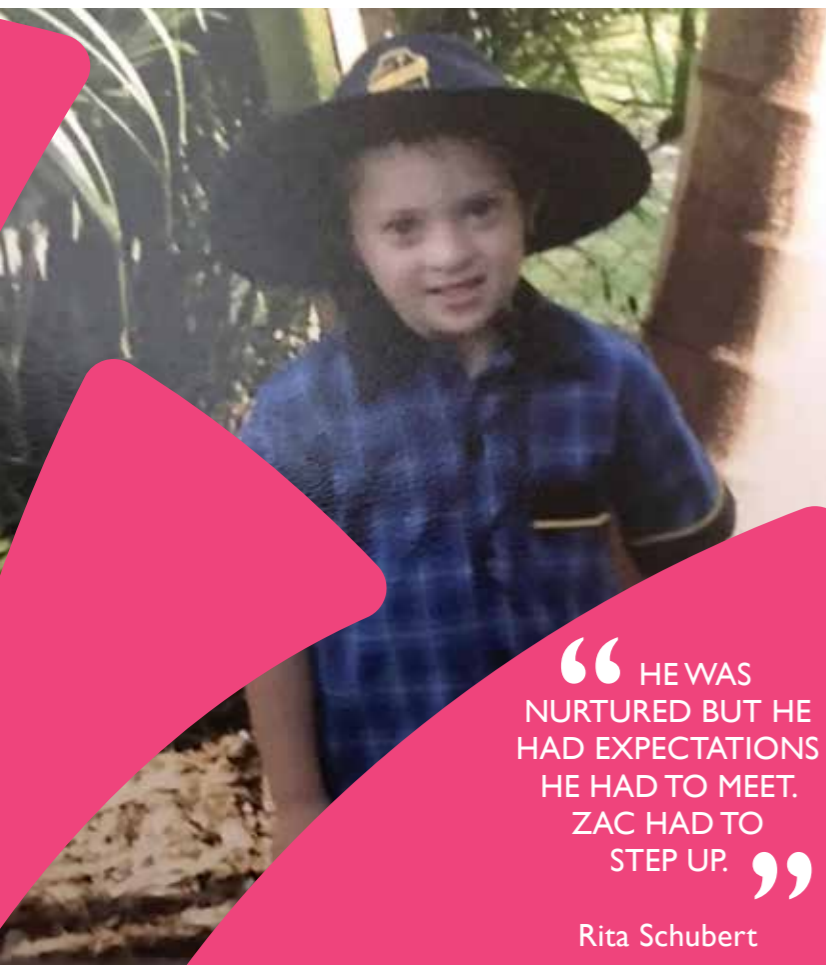
A few of the boys in the Prep year discovered they all liked to camp. So they talked their parents into going camping on the May long weekend! I was able to see that the boys just treated Zac in an ordinary way – just one of the boys. To this day, we still camp with those families on the May long weekend.

It was testament to his inclusion that in Grade 7, Zac was voted by staff and students to be Vice-Captain of the blue athletics team. This was one of my proudest moments.

Primary school really set Zac up well. There was a lot of give and take but the key was no one ever just gave into Zac because of his disability. He was nurtured but he had expectations he had to meet. Zac had to step up.

Zac created great long lasting friendships from primary school and Zac's best friend even changed his high school choice to stay with Zac. On graduation night, it was so heart-warming to take photos of the boys together, best friends since beginning of Prep.

High school was a totally different experience to primary, but the majority of the time, all was still positive. We chose a very large State high school, with an enrolment of 1800 students compared to the 400 at primary school, with a special education unit attached.



“ HE WAS NURTURED BUT HE HAD EXPECTATIONS HE HAD TO MEET. ZAC HAD TO STEP UP. ”

Rita Schubert



“ THE END PRODUCT OF FRIENDSHIPS, A QUALITY EDUCATION, A REAL JOB AND MUCH MORE MAKES THE INCLUSIVE ROAD WELL WORTH TAKING. ”

Rita Schubert

In the first few weeks of Grade 8 Zac nominated for the 50 metre freestyle race for his age level (Year 9) at the swimming carnival. Everyone was very hesitant as no one believed he could swim. I was working but an excited staff member got word to me that Zac came second in his race (after much muscle-flexing!). Zac was upset with second but was on a high with all the congratulations he received.

A few days later at pick up, I spotted him coming out to the car with the HOSES. My heart sunk thinking, what has he done?! She came up with the hugest smile saying she had had so many kids seeking Zac out after carnival day. She said it was rare for students with disability to swim in the carnival, that everyone was standing screaming and cheering, and that it was one of the most memorable moments in school history!

Zac always studied the same year level subjects. Though the school had so many buildings, Zac always knew where he had to be. In Years 11 and 12, all students were fulltime in regular classes. Zac studied English and Maths (smaller classes), Furnishings (including woodwork), Home Economics, PE and his Certificate Theory. It was a full on workload as he was only attending 3 days a week with time off campus for his traineeship. Zac was pushed academically in the regular classes. He can read and write, not at age level, but pretty well. He can get by with all the basics, and has a real talent with wood work, having the opportunity to make all the same pieces as his peers. Zac thrives in this area and has a little side line business making and selling hand-crafted platters and chopping boards. His traineeship was not easy, but we are so glad he did it. He developed friendships with colleagues and he got a job from it!

Zac always had his group of mates to hang around with. He played hand ball, basketball or footy at lunch times. To help him to connect, I spent a lot of time on weekends and school holidays teaching Zac these sports. I know he is not as skilled as peers his age but he can have a rally. By Zac knowing those skills, there is always someone up for a game with him.

He would go to the movies with his mates then Maccas, or to the footy or a cricket game. He went to Southbank with friends and his mates taught him how to buy his ticket at the cinema, order his food and catch the bus. It was year 10 when Zac and his mates decided they wanted to catch the Council bus to and from school. I felt sick in the stomach, but thought he had to learn some time. On the first morning when I dropped Zac to the bus, he started to have a meltdown until a lovely girl from his drama class arrived reassuring Zac that he would be fine sitting with her. It was a huge thing for Zac and I was extremely panicky as the bus stopped across a really busy road from school. We went over a hundred times, "you must cross at the lights". That day, his bus was in an accident and he had to walk crossing about 10 busy roads! But he survived.

The school based traineeship which I had organised involved attending a workplace 2 days a week in Years 11/12. While this was great for his employability, I was concerned missing school would impact on friendships. On Zac's school formal night I was so worried that he may know only a few people, but I didn't need to worry. His formal was held at Cloudland. We had pre drinks at W Bar. My heart was sinking as we were walking towards Cloudland. Next minute I hear "Hi Zac", "You look great Zac", and Zac knew EVERYONE. He was invited to pose for photos, including with a big bunch of girls, each one telling me how they knew Zac – from English or PE, or from the shops after school. My heart was singing. I loved those girls as much as Zac!

Zac went to schoolies, staying at Southport rather than the precinct. He took the light tram up to Surfers daily. This was a fantastic experience, catching up with primary school friends and going to parties with his high school classmates. He also met so many new friends all his same age. He would never have had that experience if he was not in a main-stream environment.

Regular school has been the most wonderful experience - not always the easiest but there really is good and bad with everything. Being well included in primary school set Zac up for life. I put it down to achieving that working partnership and making sure Zac had expectations placed on him, not being able to hide behind a disability. I found being open and honest and building that relationship with teachers and the school was key, and making sure that when negative things happened that I tried not to blame everyone, but just get on with using those positive relationships to fix things so they wouldn't happen again.

The regular path isn't perfect, but I could not be happier with all the opportunities it opened up for Zac. I really want parents to know that there are other options than special schools! Pretty much every person I ever spoke to kept steering me to special education. It can feel overwhelming to not just go with the crowd, but it helps to build your own confidence so you can approach the regular school. Know that it can work, though you may need to be prepared to give a little. While there will be higher expectations put on your child, this is better for them in the long-term. Building any relationship takes time and effort, but these will pay off in the end. The end product of friendships, a quality education, a real job and much more makes the inclusive road well worth taking.



“ SEAN'S SENSE OF FEARLESSNESS, HIS ABILITY TO RELISH NEW THINGS AND TO STEP OUTSIDE OF HIS COMFORT ZONE IS TRULY ADMIRABLE ... I AM FORTUNATE TO HAVE SEAN AS A COURAGEOUS ROLE MODEL OF HOW TO LIVE AUTHENTICALLY. ”

Milly Fisher

Inclusion is natural: A sister's story

BY MILLY FISHER



Milly Fisher was born and educated in Brisbane and studied journalism and international relations before undertaking a Masters of Social Work. Her first job as a graduate was at Multicultural Development Australia as a resettlement case manager. She left to travel around Europe and has been living in London for almost 3 years. She now works as a social worker in social care with older people. She still has a passion for travelling – but promises her parents she will come “home” sometime.

“ I HAVE SEEN WITH MY OWN EYES THAT PEOPLE WITH DISABILITY MAKE OUR COMMUNITIES RICHER THROUGH THEIR PRESENCE AND GIFTS. ”

Milly Fisher

I am the eldest of three, with two younger brothers, Sean and Declan. My younger brother, Sean, has Down syndrome and I was in Grade 4 when Sean joined me at our local Catholic primary school. At the time it seemed so normal and natural for him to be joining me there; it's only now I realise the obstacles that my family would have faced.

As a child prone to shyness, Sean's presence at school meant I was forced to come out of my shell. Sean has such an enthusiastic and vivacious personality that he was difficult to miss – and within a very short time, everyone knew him. From the beginning, our parents ensured we were both actively involved in the school community and extra-curricular activities. It was a small school, but swimming was a big focus, and both of us participated in after-school lessons, squad and Monday night swim club. I may have been faster, but Sean was the “star” in terms of fans.

Whilst Sean did have some separate learning time, which Mum wasn't always so keen on, he participated fully in the shared life of the school. He was included in ordinary rituals of school such as sports carnivals, camps, assemblies and excursions.

He always joined in with great enthusiasm which was duly noted by all. I would even claim to my parents that we were the most popular family in school because of Sean's ability to draw a crowd and know everyone in school. Going to the local shops was a lesson in celebrity for sure!

As a protective, and arguably bossy older sister, this didn't change once we were at school together. I felt a sense of duty to watch over my brother and make sure he was included. For the most part, my anxieties were eased, he had a supportive group of friends with whom he started and finished school. Whilst I have overwhelmingly positive memories of our schooling together there were also some challenges.

School can be a difficult time for anyone and almost no child is exempt from rejection and some form of teasing or name-calling (at some point). Certainly, there were experiences of this, and I can remember one occasion where an older boy came up to me at lunchtime using offensive words about Sean, asking why my brother was "demented". This incident and some others were distressing at the time, but in retrospect these were few and far between and overwhelmed by more positive experiences. I'm sure I may have felt embarrassed at times (like when Sean decided to wear Mum's undies over his shorts and do a dance in the school quadrangle) and had moments of pre-teen sensitivity where I felt overwhelmed that our family was 'different' but with a supportive family and school network these issues didn't seem too significant.

Sean's sense of fearlessness, his ability to relish new things and to step outside of his comfort zone is truly admirable. He is a lesson in not being too self-conscious. As a sibling, I am fortunate to have Sean as a courageous role model of how to live authentically. These experiences have been formative and developed my own resilience and confidence.

I recall Sean being chosen by his class to play the lead role for his Year 7 Easter concert. For me, this was symbolic of the significant impact Sean had on his class.

Not only was Sean able to share his own unique strengths with his peers, but they were able to benefit from being exposed to his 'difference'. Research consistently demonstrates the benefits of inclusive education, but I have witnessed first-hand how it can increase understanding and acceptance. I have seen with my own eyes that people with disability make our communities richer through their presence and gifts. This isn't just family bias; people regularly tell me how much they appreciate Sean and have learnt from him.

Sean was embraced by the whole school community, in particular his class, but my school friends also greatly appreciated his trickster personality and zest for life. When we hosted birthday parties at home, Mum was always keen for some extra hands, so often my friends and I were enlisted to help, and they would fight over the chance. Connections continued to be nurtured across life, and my friends have all embraced Sean – attending his 18th and 21st birthdays (and inviting him to their celebrations), joining us at the pub or nightclub, housewarming parties, BBQs and even a university ball.

“ WE WERE THE MOST POPULAR FAMILY IN SCHOOL BECAUSE OF SEAN'S ABILITY TO DRAW A CROWD AND KNOW EVERYONE IN SCHOOL. ”

Milly Fisher



“ I AM POSITIVE AND HOPEFUL THAT MAINSTREAM EDUCATION WILL SOON BE CONSIDERED THE DEFAULT. ”

Milly Fisher

Fear of rejection in the school environment is understandable when we know that bullying is such an issue, but my own observation has been that children have a natural capacity to include those with disability. Further, I strongly believe that inclusive education demystifies disability for children and can set the foundation for life-long inclusion and a more accepting community. Sean continues to live an inclusive life, and his school friends invite him to events and are alongside him to celebrate important milestones, like moving into his own apartment.

I now live in London, but my brother continues to be embraced by my own friends who live in Brisbane, or they catch up when he's visiting me. He was super excited to hit the English pubs with a bunch of Aussie friends last time he visited. It was all very regular – similar to my own relationships with the siblings of my closest friends.

Sean lives a full and meaningful life – he works, volunteers, lives independently and has an active social life. Despite the challenges, regular education gave Sean the preparation he needed to take his place in the world – with pride and LOTS of connections. Sean was welcomed into the folds of our school community, but I know it took a lot of effort behind the scenes. I do see him and my family as paving the way for others.

I am positive and hopeful about the future of inclusive education for all people with disability. I am positive and hopeful that mainstream education will soon be considered the default. I am positive and hopeful that, with the right commitment, all children with disability will get the support they need to grow and develop to reach their full potential in their local schools and communities.

“ DESPITE THE CHALLENGES, REGULAR EDUCATION GAVE SEAN THE PREPARATION HE NEEDED TO TAKE HIS PLACE IN THE WORLD – WITH PRIDE AND LOTS OF CONNECTIONS. ”

Milly Fisher





Embrace difference. Give Inclusion a Go

BY NIA MICHELLIS



“ I WENT THROUGH YEAR ONE TO YEAR SEVEN WITH SEAN AND HE WAS ENTHUSIASTIC, A BUNDLE OF FUN, WOULD PARTICIPATE FULLY AND GIVE EVERYTHING A GO, BUT MOST OF ALL WOULD PUT A SMILE ON OUR FACES. ”

Nia Michellis

Evyenia (Nia) Michellis is 23 years old and is a Speech Pathologist who is passionate about helping others across the lifespan to swallow safely and communicate. She also enjoys singing, tennis and going on adventures/short hikes. She grew up in Brisbane but has been living and working as a Speech Pathologist with paediatrics and adults across the lifespan in Far North Queensland for almost 12 months.

“ THERE WAS NEVER ANY QUESTION ABOUT CONTINUING MY FRIENDSHIP WITH SEAN AND I AM SO BLESSED TO HAVE A FRIEND LIKE HIM ... IT HAS BEEN GREAT TO SEE HIM SUCCEED IN WORKING IN OPEN EMPLOYMENT, LIVING IN HIS OWN HOME, VOLUNTEERING, EXCELLING IN HIS FITNESS AND REMAINING THE FUN FRIEND HE HAS ALWAYS BEEN. ”

Nia Michellis

My experience with inclusive education began when I was in Year One. I was in a split One/Two composite class and my twin brother, Yanni, was in the Year One only class so I mixed a lot with his class. My friend Sean, who has Down syndrome, was in that class. I honestly don't recall thinking of him any differently or having any negative views. After all, we were a group of young children there to learn and socialise. We were all different heights (my brother and I were the shortest in the year all the way until year 12!), had different birthdays, different ethnicities, different personalities, different appearances and different strengths so I never defined Sean by his disability. At a young age, all I remember thinking was that Sean was lucky because he had a lovely teacher aide, Mrs C, and one on one time which I always wanted. I went through Year One to Year Seven with Sean and he was enthusiastic, a bundle of fun, would participate fully and give everything a go, but most of all would put a smile on our faces.

Sean actively participated in the school concerts, sports days, disco nights, swimming carnivals, assemblies just like all of us did. He also came on our school camps. They were fun! I also remember Sean's dance moves appearing at the camp Talent Show night. All of us looked forward to Sean's dance moves!

I vividly remember the early years weekly swimming lessons where Sean, myself, my brother and some other peers were in the 'support swimming' group. Fast forward a few years and Seany graduated from that class and moved on to be with the 'big kids' and showed us all what he could do. He won swimming races and attempted hard strokes like butterfly which I was not willing to try. He was there trying to convince me to 'give it a go' but I got out of that one by being up in the grandstands cheering him on. His "can do" attitude and self-confidence was really impactful and, to this day, I continue to be inspired by him.

During the high school years, I knew I wanted to continue my friendship with Sean. Harriet, Rachael, Sean, Yanni and I would catch up for 'mini reunions' in highschool. For example, going to the movies, to Southbank or to one of our houses, and towards the end of highschool Sean started to invite us over (which was when the tradition of him cooking us sausages started). When we went to Southbank, Sean would often greet us with a grin after hiding behind trees which lined the footpath, waiting to surprise us. One of my strong memories in highschool was when Sean and I both got the chance to attend his school dance. I wasn't going to go in when I found out my friends had cancelled but I then saw Sean. He had a big smile and was shocked to see me. He then called out to me and invited me to enter, so I convinced myself to stay. Soon enough he was introducing me to everyone and we spent the night having such fun dancing on the dancefloor. He even brought back his moves from primary school!

The next stage of life was university. I started my degree in 2014 and in my last couple of years, Sean's mum mentioned that he was keen to go to uni and try a subject or two. I thought 'what a great idea'. We aimed to catch up for coffee every couple of weeks at uni and we celebrated his 21st, my 21st and all the birthdays in between together. Sean loves to party and took every birthday and Halloween as an opportunity to host a party with his friends from primary, high school and work! I remember his highschool anthem came out at one of the parties; you can imagine how loud it was with a balcony full of men, and Sean there belting it out. It was always so nice to see him so happy and have so many friends around him.

After this came real life, adulthood, daunting for the both of us with many unknowns. I graduated uni in 2017, moved to Tasmania and am now living in Cairns. Our friendship did not end here. We would catch up via phone or FaceTime (and still do) and Sean would also send multiple messages on Facebook telling me he missed me and asking when I would be back. Last year I was fortunate to travel back to Brisbane and celebrate Sean's move into his own apartment, what a milestone! We celebrated with a brunch on his balcony and he made us feel so welcome. He helped his mum cook up a feast, literally! Sean was in charge of the oven and sausages and his mum prepared the eggs for us. Sean made sure we each had a fancy glass with juice to go with the meal and then took us on a tour, and was so proud of his apartment. Yanni and I later attended his housewarming party – the unit was full with his friends. I thought, 'look at him go, more of an adult than I am'.

There was never any question about continuing my friendship with Sean and I am so blessed to have a friend like him. He's genuine, has a great sense of humour, he tells you how it is and does not let his disability define him or limit him. It has been great to see him succeed in working in open employment, living in his own home, volunteering, excelling in his fitness and remaining the fun friend he has always been.



“ SEAN ACTIVELY PARTICIPATED IN THE SCHOOL CONCERTS, SPORTS DAYS, DISCO NIGHTS, SWIMMING CARNIVALS, ASSEMBLIES JUST LIKE ALL OF US DID. ”

Nia Michellis



My stance on inclusive education has been shaped by my experience going to school with Sean, a relative with a disability and my career as a Speech Pathologist.

My view is that everyone is different and unique and that having a disability should not define where a person learns. I am fortunate to be a Speech Pathologist in a time where inclusive education plans are developed to support children who require a bit more assistance to learn the curriculum and participate at school.

Yes, there are hands down going to be challenges with children with disabilities being in a mainstream school for both the child, the child's parents and the professionals, however I also believe there are many positives to inclusive education. Parents know their children best and it is so important for professionals to be open, flexible and have a 'let's give it a go' approach and work collaboratively with the family, rather than make a decision for the family. I know our school system isn't always perfect at accommodating everyone's needs and I am not sure how inclusion in our current system would work for everyone, but I truly believe it's better to give the inclusive path a go and to try to figure things out, rather than assume there will be problems, not even try, and always wonder.

I would love to see sign language become a language taught in daycares and throughout primary school, even incorporated into the curriculum, not only to benefit those with a disability who rely on sign as their primary means of communication, but also for the Deaf population. It is such a valuable form of communication for anyone to know.

It is so important for everyone to remember that children with and without a disability come in all different shapes and sizes and there isn't a one size fits all for a person or their school environment. Everyone has differences in their physical appearance, cognition, language, speech, fine or gross motor skills, hearing, and vision for example and having a disability should not define a person. Providing opportunities for young children and having a 'give it a go/can do' attitude are the best things that a family and community can do as this will also impact on an individual's opportunities later in life.

So, that's my main message I'd like to send to everyone out there, 'give it a go' and be open minded. That is probably something that connects Sean and me. I am someone who always has a lot of goals and projects, and I can see that in Sean too. He has ambitions for himself, and being included in a mainstream school probably helped expose him to lots of different role-models who he may otherwise not have had the chance to cross paths with. Some may only see limitations when they see a person with an intellectual disability, but everyone has areas of strength and areas for improvement and knowing Sean and others, I know that if we provide opportunities and "give it a go" we are already ahead... And boy can I tell you how amazing it has been to see Sean continue to learn new skills (knowledge based and life skills) since graduating highschool!!

I have honestly seen ongoing improvements in his understanding, cognition and even social skills which I feel has been because he has been included in all things: school, university, work, and extra-curricular activities. Not everything works out as planned but with a "can do" attitude, surrounded by supportive friends and family, the ride is worthwhile and everyone learns a thing or two.

“ PARENTS KNOW THEIR CHILDREN BEST AND IT IS SO IMPORTANT FOR PROFESSIONALS TO BE OPEN, FLEXIBLE AND HAVE A 'LET'S GIVE IT A GO' APPROACH AND WORK COLLABORATIVELY WITH THE FAMILY, RATHER THAN MAKE A DECISION FOR THE FAMILY. ”

Nia Michellis





“ I FIND THAT I STILL CANNOT RESIST THE AMBITIONS OF INCLUSION. IN SPITE OF THE DIFFICULTIES, I CONTINUE TO FEEL UPLIFTED BY THE POWER OF SUCH A VISION. ”

Glenys Mann

Reflections from the end of the tunnel

BY GLENYS MANN



“ WHILE PARENTS USUALLY HAVE CONSIDERABLE AUTHORITY IN EDUCATION DECISION-MAKING, I FOUND THAT IT TOOK EFFORT AND EVEN COURAGE TO CLAIM THAT AUTHORITY. ”

Glenys Mann

Glenys Mann is currently a Lecturer in Inclusive Education at QUT. Glenys has taught in Queensland state schools, and worked as an education consultant with the Down Syndrome Association of Queensland, as well having roles in a number of other community organisations focused on furthering inclusion. Glenys was a long-term member of the inclusive education network of Qld Parents for People with a Disability and authored QPPD Publications “Diving for Pearls” and “I Choose Inclusion”.

Her PhD was completed in 2017 at UQ; “An exploration of parental decisions to transfer children from regular to special schools”. This contribution includes edited reflections originally published in this PhD thesis.

It is nearly ten years since my son left school. Even now, it is difficult to slow the thoughts and feelings that come flooding back when I think of those years. Did I make the right decisions about his schooling? Were regular schools the best way to go? In the balance of his school life, did the joys and opportunities outweigh the hurt, frustrations and struggles? I recall a meeting near the end of Jack’s school years where all these questions seemed to come at once.

‘It is 2009. I am sitting in a meeting room at my son’s high school. It is a room that I have been in many times before. I am very tense but act in an upbeat and friendly way. These people are good people; I know them well. We have been through many years together; first with my two daughters and for the past three years with Jack. I have a lot of respect for them, and know they are trying to do their best. I know they want to do the right thing, but they are not sure what that is. I am very aware that the Principal wants me to reconsider my desire to have Jack remain in the school for Years 11 and 12. He has gently raised alternatives a number of times. I look around the room and think that it must take a lot of people to wear one mother down. The whole leadership team is here; this must be the meeting that is meant to change my mind.

As I sit there waiting for the meeting to begin, I think back to when Jack started school all those years ago; I knew that it was not going to be easy to have him follow in his sisters’ footsteps. I wanted him to have an inclusive education, but I knew this would take hard work. Hard work I didn’t mind, particularly if it meant that Jack would be part of his family school and his neighbourhood community. I was willing to do what it would take because I believed then, and still do, that people are better together, and this meant everyone, not just Jack.

I was clear that if he were to be part of society, school was the place to start ... not just for his sake but for ours too. How could we become more inclusive, if we didn't have opportunities to learn about what that meant and what it would take? I had felt that there was no choice but to jump in and see what would happen.

I hoped, when I started the schooling journey with Jack, that I would find teachers who would accept him as he was, and who would work to create a school in which he had a place. I also believed, perhaps a little naively, that Jack's presence would open up a space for teachers to learn as well; that he would be a pioneer in his schools and that children who followed after him would benefit from the difference his presence had made. I believed that once teachers knew of the evidence for inclusive education (which, of course, I would enthusiastically share), they could not help but see the rightness of inclusion and share my vision and passion for such a venture. I did find such teachers, but they were few, and now, with the benefit of hindsight, I know it WAS naïve of me to expect I would have such influence.

While parents usually have considerable authority in education decision-making, I found that it took effort and even courage to claim that authority. Very early in Jack's schooling I was shown "quietly and respectfully" where the power lay. I had attempted to raise (also respectfully, and after hours of planning) my concerns about the large amounts of time that Jack appeared to be separate from his classmates. Firmly and kindly I was told that the school "was doing everything they could and could do no more"; if I felt that more was needed I was very welcome to look elsewhere for a suitable school. The message to "not to rock the boat" was loud and clear. Claiming my authority as Jack's mother while maintaining healthy and positive relationships with school staff was an ongoing dance of diplomacy. Sometimes we were in time and the movement was rhythmic and fluid; at other times we were out of sync and stood on each other's toes. Never, though, did I forget who was taking the lead.

Ten years later, in that meeting room, I am filled with the mixed memories of Jack's time at school so far. It has been the best and worst of times, and I am trying to make some sense of it so that I can decide what to do in the school years that are left. Inclusion feels heavy on my shoulders, a philosophy of what SHOULD be and a promise that has often frustrated rather than delivered. I find that I still cannot resist the ambitions of inclusion. In spite of the difficulties, I continue to feel uplifted by the power of such a vision, but when one is NOT included authentically, then what is one to do? Words... dreams... hopes... they have naught to offer me as Jack's mother than something to believe in and to yearn for.

“...OPPORTUNITIES THAT HAVE EXPLODED INTO JACK'S LIFE IN HIS SECONDARY YEARS (CAMPS, ORCHESTRAS, KAYAKING, ABSEILING, SOCIAL EVENTS, PARTIES) AND THE FRAGILE RELATIONSHIPS THAT HAVE SLOWLY BLOSSOMED BETWEEN JACK AND HIS CLASSMATES.”

Glenys Mann



I am acutely aware that I cannot do this on my own; for Jack to be included I need his teachers to believe in and yearn for inclusion too. Trying to "make" inclusive education happen for my son has been powerful and meaningful work, but it has left me feeling tired, and more than a little puzzled as to why it has been so hard.

This is a time of serious reconsideration about what I want out of school life for Jack. Has the matter of what a good school life means for him changed since I had last thought about this? His was a good school but what about Jack's school life so far? A "good" institution does not necessarily equate to a good school life and I am considering anew what will be best for Jack. His learning (and my own strong belief in his ability to learn) is uppermost in my mind but perhaps even more important to me at this final stage of his schooling life are the wide-ranging and abundant opportunities that have exploded into Jack's life in his secondary years (camps, orchestras, kayaking, abseiling, social events, parties) and the fragile relationships that have slowly blossomed between Jack and his classmates. What would I be exchanging for these hard-won friendships and opportunities should I decide it would be best for Jack to leave the school?

Jack is my primary consideration as I think about schooling options, but his needs aren't the only ones on my mind. I find it impossible to put my own feelings aside in these deliberations. I long for his schooling to feel easier, and to not be constantly on call. I am tired of the difficult conversations. I want to feel safe in handing over the matter of Jack's education to someone else (as I had done with my daughters)—to knowledgeable, confident teachers whom I can trust to be on Jack's side and to have faith in his ability to learn and to participate. What is more important to me? The prospect of a more peaceful life that, perhaps, a special school might offer? Or the opportunities for connection, growth and continuity that I know will only be his if I persist with his current enrolment?

As I sit in the school meeting room and feel the wave of professional opinion about my son's future wash over me, I try to weigh up these deliberations and decide what will be best for Jack's remaining school years. I feel by my side the spectre of other parents who, like me, have also lived, or tried to live an inclusive life with their children with disability. I think about the stories they have told about similar meetings and their own decision-making, and feel deeply, my own experience now, the weight of the decision that I must make.

In the end, the vision of a meaningful, good life (and what that would take) stayed in focus. Jack remained where he was, and I have no regrets about my decision. Despite how difficult and painful inclusion was to pursue at times, in his final year many of the pieces seemed to fall into place and Jack's life was full of fun, camaraderie and celebration (as Year 12 should be). He remembers his years at school as "excellent" times, and they gave him expectations for the future and a group of friends that remain with him today.

These memories are uplifting and satisfying and remind me of the importance of this complex and difficult change we are making to a better way of being in community together. I wish I could go back to that mother I was, to remind her to relax and stay focused, and reassure her that she was on the right path.



“ IN HIS FINAL YEAR MANY OF THE PIECES SEEMED TO FALL INTO PLACE AND JACK'S LIFE WAS FULL OF FUN, CAMARADERIE AND CELEBRATION. ”

Glenys Mann

“ WE KNOW WE WOULD BE BRAVE AGAIN, TAKE THE FLACK, WEAR THE FRUSTRATIONS, AND KEEP GOING. MENA WOULD EXPECT NO LESS OF US. ”

Margaret and Jeremy Ward

“ WE WANTED MENA TO BE SEEN AS A CHILD, AND ULTIMATELY AN ADULT, WHOSE HUMAN COMMONALITIES FAR OUTWEIGHED HER DIFFERENCES. ”

Jeremy and Margaret Ward



Lessons from the Past

BY MARGARET AND JEREMY WARD



Jeremy and Margaret Ward are parents whose eldest daughter, Mena, lived with disability and required support to live in her own home, which she did successfully for over 10 years. Jeremy's older sister also lived with a significant disability all her life. They both have many years' experience in disability advocacy. Jeremy's interest is in the law as it relates to people with disability and in assisting families to plan for the future. Margaret has focused on housing. *The Shouted Goodbye*, Jeremy's account of Mena's life, was published in 2015.

Towards the end of 1989, after Margaret returned from a study trip to Canada and the USA, we embarked on a campaign to have our daughter, Mena, attend a mainstream school full-time. Until then Mena had been going to a special school four days a week and a local primary school for one day a week. Mena was then aged 10.

The reasons for our making this decision are set out in the following extract from *The Shouted Goodbye*, which Jeremy wrote after Mena's death in 2009.

At that time in Queensland, in the late 1980s, there were some children with physical disabilities, who could compete academically, in wheelchair-accessible local schools. There were also some with mild intellectual disabilities in their local schools, children who needed very little assistance, if any, with everyday personal tasks such as eating lunch. We did not know of any children like Mena, with significant multiple disabilities, attending their local school full-time.

We knew from the experience of Mena attending her primary school just one day a week that a move to full-time would be a challenge for the education system. Whenever there was an issue too hard for the school, we were asked to keep Mena home. It might be that her aide was sick, or that the class was going on an excursion to an inaccessible destination, or that they needed Mena's aide to supervise other children on sports day. While Mena was attending only one day a week, the school would never need to make an effort to include her. It was as if the school was doing us a favour for Mena to experience the everyday activities of school life.

Before Margaret went overseas, we had begun to firm up our vision for Mena. We had both been exposed to the theory and practice of Social Role Valorisation, known as SRV, developed by Wolf Wolfensberger, whose analysis of advocacy had become so influential in our lives.

“ THE FIRST WAS TO CHOOSE OUR BATTLES, KEEPING OUR CHILD FRONT AND CENTRE IN OUR ADVOCACY. ”

Margaret and Jeremy Ward

Drawing on what we had learnt we fine-tuned our vision to one simple statement: that Mena would be a valued citizen in her local community. Over many dinners after the children were in bed, we talked about what that meant until we thought we were clear and could explain it to others. Every word of “valued citizen in her local community” was important and meaningful.

First, it meant we had to develop strategies aimed at Mena being valued because we had learnt from SRV theory, and our personal experience, that people with disability are frequently devalued members of our society. We needed strategies that would counter that devaluation and assist Mena to be valued, not only by those who knew and loved her, but by the broader community.

Second, we wanted Mena to be seen as a child who would grow to become a citizen in her community, not as someone who was different or special, whose life would be lived on the sidelines, in special schools and services such as those offered by the [Cerebral Palsy] League, which the general public knew about only through fundraising activities. We wanted Mena to be seen as a child, and ultimately an adult, whose human commonalities far outweighed her differences. If she did everything that typically other children did in her community, we believed she would be seen as someone expected to do what other children did, rather than being singled out for activities that took place somewhere outside her community.

Third, we wanted Mena to be part of her local community. There was much talk about people with disability being supported to live in “the community”, but we found much of that to be imprecise and ill conceived. For Mena to be valued as part of her community, we needed to clarify what, and where, her community was. That led us to focus on her local geographical community, rather than on a broader community of interest. We believed that, over the long term, a focus on her geographical community would help us to meet her fundamental needs of home, love, work, good health, fun, relationships and friendship. Time and again we returned to our vision for clarity and strength of purpose. We concluded that, for Mena to become a valued citizen in her community, she needed to attend a local mainstream school. [*The Shouted Goodbye*, Boolarong Press, Brisbane, 2015, pages 36-37]



“DRAWING ON WHAT WE HAD LEARNT WE FINE-TUNED OUR VISION TO ONE SIMPLE STATEMENT: THAT MENA WOULD BE A VALUED CITIZEN IN HER LOCAL COMMUNITY.”

Margaret and Jeremy Ward

After a hard-fought campaign, and with generous support from a group of people we asked to assist us, we achieved our goal in July 1990. Mena spent 18 months full-time at the local primary school, followed by six years full-time at her local high school. Now, as we look back, we can reflect on our decision and on Mena’s school experience.

In 1990, inclusive education for children with more complex needs was extraordinarily rare. We also experienced teachers smoking in class, taking photos and videos without permission, and showing scant regard for confidential information. So, there have been many changes for the better in schools since then. Yet, some unhelpful practices continue.

The school system is like any institution. If challenged, it will seek to protect itself, and ultimately, look after its own. Like the Royal Commission into Institutional Responses to Child Sexual Abuse has shown, institutions are slow to learn and do not take criticism kindly. Heroic parents who take on the education system to make change will be sorely disappointed when their personal wins do not translate to systemic ones. We learnt four important lessons.

The first was to choose our battles, keeping our child front and centre in our advocacy. Our valuable energy could have been wasted sitting on school committees or taskforces developing policy that would change with the next principal. We found it was more important to find allies who shared our vision, supported us in practical ways, and kept us informed and alert to what was going on.

The second was to listen to our intuition. When we had a sense that things were not going well, we were usually right, despite the assurances from the school that they had everything in hand. Perhaps the rhetoric of “parents as partners” is more meaningful now and communication between concerned parents and school is open, honest and helpful. We hope so.

The third was to realise that the school years are relatively short in a person’s life. All the worry it took to safeguard Mena’s inclusion disappeared once school was over. There were many possibilities for Mena out there in the real world, and it was up to us to dream them up and make them happen. We needed a daring and positive plan for adult life well before school had finished. With the support of our allies, we created an adult path to inclusion and Mena never looked back.

Finally, we would do it all over again. Even though Mena left without any enduring friendships or a useful education, she was clear about her place in the world—she belonged. She was ready to get a job and to leave home like her school mates. If we had been timid and taken the easier route through the special school system, we would have remained timid and agreed to soul-numbing “post-school options”. So, we know we would be brave again, take the flack, wear the frustrations, and keep going. Mena would expect no less of us.





“ MY MOTHER ALWAYS BELIEVED THAT HAVING A DISABILITY DID NOT MEAN I SHOULD BE “COTTONWOOL BALLED” OR PROTECTED TOO MUCH FROM THE CHALLENGING TIMES THAT ULTIMATELY WE ALL HAVE TO GO THROUGH. MY MUM ALWAYS GAVE ME THE BREATHING SPACE TO FALL - SOMETIMES LITERALLY!

Marlena Katene ”

10 things I love about having an inclusive life

BY MARLENA KATENE



Marlena is a Gold Coast based entertainment journalist who hasn't let not speaking verbally or using a wheelchair limit her life opportunities. She has built up an extensive portfolio of interviews with everyone from Snoop Dogg and Russell Brand to the Dalai Lama. The oldest of two children, her mother Pam always instilled in her the benefits of real inclusion and why it is vital to have non-paid people involved in her life. Post school, Marlena went on to complete a business and journalism degree whilst travelling the world, authoring two books and running a small business. Her interests include travelling and music, and she loves her local beach Burleigh.

“ I ENJOY HAVING A CAREER. I AM A FREELANCE JOURNALIST, AS OPPORTUNITIES ARISE, I ADAPT AND TAKE THEM.

I NOW HAVE A COMMUNITY OF FELLOW JOURNALIST AND FRIENDS. THEY SUPPORT ME IN CAUSES THAT ARE CLOSE TO MY HEART. IT'S AN INCLUSIVE LIFE. ”

Marlena Katene

My name is Marlena Katene. I am excited to share some of my journey. I have cerebral palsy but won't bore you too much with that. What you may not know from the outside is all the opportunities that I have had due to living an inclusive life from the beginning.

Now that I am 29, I often wonder what gave my mother the strength and foresight to see that an inclusive education was the only option for me all those years ago. Why, when the professionals told her special school was best for me, did she stand her ground and keep her eyes on her own vision for me? I love my life. I have a good mix of friends, a career as a music journalist and have had many other opportunities and achievements. I am not too sure my life would have panned out the same way if my mother had listened to some other people! So here are my top ten guiding principles to keep pursuing and loving my inclusive life.

1. Life is both fun and challenging

I go through hard times like anyone else but because I have been included, I have an awesome bunch of people that get me through these times, with minimal long term impact on my well-being and state of mind. My mother always believed that having a disability did not mean I should be “cottonwool balled” or protected too much from the challenging times that ultimately we all have to go through. My mum always gave me the breathing space to fall - sometimes literally! – to experience life warts and all. We all need to fail to succeed so parents please give your kids some breathing space.

2. Safety and control over my life

As a 29-year-old woman that relies on people for basic needs, safety and control is so important in my life. My day literally is at a standstill if I don't have a variety of people in it. I am fortunate I have always lived in the beautiful Burleigh heads on the Gold Coast. Not saying my back yard is better than yours – but it is pretty damn good! Being part of the Burleigh community ensures I am safe, which then allows me to set the direction for my life, try things and grow as a person. Having cerebral palsy, literally some days my body movements are so bad I can't control my body or many things. Despite this, I feel I have complete control and autonomy over the decisions in my life, even if others don't agree with them. Having a disability doesn't stop one for making dumb decisions at least some of the time.

3. Expectations

From an early age I had expectations placed on me. When I was in grade 3, I went to my friend Ali's house after school. In her bag, she had a note to fill in to buy a recorder for our music class. To keep the story GA rated, when my mother found out I hadn't got that note, she "reminded" my school principal that she had a strong expectation that I would buy a recorder and be part of my class. Now due to my cerebral palsy, I couldn't blow in a recorder but the fact that I totally sucked and would fail at every attempt to blow in the damn thing was irrelevant. My mother was the expert. Professionals told her not to expect too much from me, "as long as she is happy". But she persisted with her high expectations, including that I would have a real job with real pay. This led to my first business – Burleigh Bouncers – which has provided me with financial means to achieve many other inclusive life goals, and being included and being known happens naturally in my work environment. As well as being a business owner, I am a published author of two books: a kids' book and a photography quote book. Having high expectations doesn't mean I won't fail. There are risks, but risks come with rewards!



“ HAVING FRIENDS AND RELATIONSHIPS IN LIFE IS THE ONLY WAY WE CAN TRULY BE HAPPY OR WHOLE AS HUMAN BEINGS. I ENJOY TRAVEL, ADVENTURE, MUSIC AND THE BEACH; SHARING THOSE WITH FRIENDS MAKES MY LIFE COMPLETE. ”

Marlena Katen

“ HAVING AN INCLUSIVE LIFE MEANS I HAVE GOALS AND KNOW I WILL BE SUPPORTED IN THEM. ”

Marlena Katene

4. Friendships and relationships

Having friends and relationships in life is the only way we can truly be happy or whole as human beings. Support from friends, family and community relationships have been central to all my achievements. I enjoy travel, adventure, music and the beach; sharing those with friends makes my life complete. I love my friends. I still keep in touch with school friends since primary, albeit not as often as I would like these days. Kendall has been a good friend from grade 6 and even though she is married now we regularly catch up. I have friends from my Business management course, uni friends, older friends and girlfriends around my own age. Life is good and my friends don't really care about my cerebral palsy. It's a lot more fun hanging out with friends over paid workers in environments such as movies, concerts or going to the local pub. Inclusion allows for friendships. My friends are my best asset!

5. Experiences

Inclusion allows me to have rich experiences. I have had many, many, MANY experiences, both for work and socially. I am totally addicted to travel – visiting 38 countries so far. Two years ago I went to China. It wasn't my favourite travel experience and I probably won't go back but it was fun and made possible through an inclusive life. Basically I didn't need a "carer" but found someone that wanted to "check it out" and we went pretty much 50:50 with all associated costs. Most of my trips have been like this. I don't take this for granted. If my mother had chosen the segregated journey, I can't see how this would now be possible. Luckily I don't need to rely completely on the NDIS, but can use natural supports to maintain my travel addiction.

Inclusion has ensured I can meet my needs in ordinary and holistic ways. About 18 months after I finished school, like many other teenagers, I had lost some friends and it was affecting me as I am happiest when I have heaps of friends. Basically it was a pretty suckful time. So we thought what is the typical thing a non-disabled 18 to 21 year old might do? Travel! I did a few short trips and then planned some Contiki tours – 2 different ones over 3 months, with the longest being 28 days. I took a support person, Bert, who had known me a really long time, but after 3 days I didn't really need Bert for a majority of the time. I had people my age pushing my chair, giving me drinks, feeding me and basically just being young and stupid with me. Through living an inclusive life, I have many examples of receiving natural help, with resulting lifelong friends through those experiences. I have many communities but to name a few my music community, base jumping and skydiving community and my travelling buddies. Life is about experiences and connections. I have grand dreams of being financially successful, but life is truly to enjoy fully and fill with awesome experiences.



6. Goals

Having an inclusive life means I have goals and know I will be supported in them. Most of the people in my life know my goals and believe in my ability to achieve them. I shudder to think what "goals" would have been developed for me had my life been segregated as a disability service client. Many of my goals, especially my work goals, would not be feasible if I was segregated. My mother always taught me to think ahead in setting goals. Bert has taught me to set business goals and has helped me create income streams from very little money. Being part of an inclusive community allows me to achieve my goals more quickly. When I wrote my first book, my expenses came to \$4500 and originally, I thought I might have to crowd fund. Someone suggested preselling the book on Facebook. To my surprise my community of friends rallied, and before it even went to the printer, I had sold \$3750 worth of books. Within a month, I had turned a profit. Now I have re-invested the money and have a strategy where I will always have money for the next book. Through meeting my goal of being a published author, I have sold about 4400 books and have ensured another income stream.

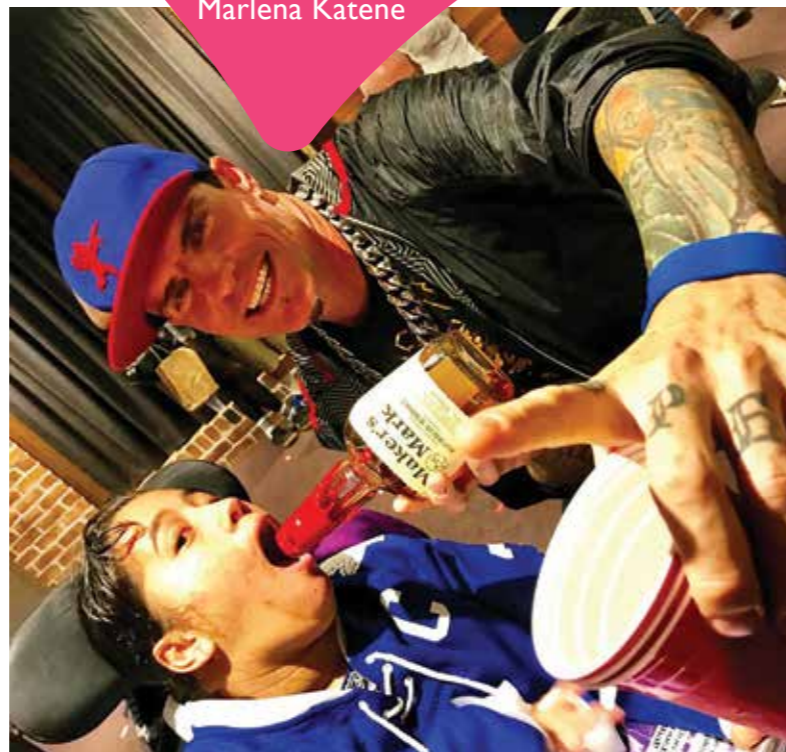
7. Resilience

I have already spoken about risk and rewards. My mum was often looked at sideways by people that questioned her decisions at time. I love my mother more than anything else because she gave me a thick skin. Sometimes crap things happen. In my final year of high school, I was lucky enough to go on a school trip to Japan, but the full story was that the school had cancelled that trip the year before because they didn't believe they could support me in that environment. Luckily with a change of Principal (to one with an open mind!), I got to have that amazing experience. The trip broke down barriers with my teachers and peers. It gave me an outlet to connect with them on another level. With all the hard work that my mother and I had done to be included, it was the best way to finish my schooling, and worth persisting to get there.

If I was segregated I think some of the things that have happened in my life would be so traumatic. In recent years, I had struggles with segregation at an Eminem concert in Brisbane and also at Pink concert in Sydney. In a nutshell we had VIP front section tickets and due to my wheelchair we were relegated to the back wheelchair section. This isolation was forced on me; it truly was rubbish being segregated in my music community, but having a thick skin ensures good will be coming from this situation. Already we have seen massive changes in this space in the last year. My inclusion throughout life allows me to be resilient and have a good life despite some not so positive situations that pop up from time to time.

“ INCLUSION
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Marlena Katene



8. Community

My community is AWESOME! Inclusion is all about community and choosing which ones we wish to be part of. Segregated communities or being forced to be just part of one community limit one's potential as well as the means to give back and contribute. Travel allows me to see other communities and how other people live, but my Burleigh community is where I feel most at home. Knowing I can walk from my house to the beach by myself and have a dozen or more people wave or say hi is the best. People stop and engage and try to facilitate my communication. One of my social communities is my skydiving / base jumping communities. I live with my best mate, Bert, and he got me into skydiving; 3 years ago I was the first person in the world with CP to BASE jump. We are welcomed by crazy athletes all around the world. Initially I was reluctant, but now I am hooked and have made friends from all over the world – including from France, Idaho and even Oman.

9. Opportunity

I am blessed that throughout my life, I have had so many opportunities – work, career, social. To be blunt, there are more opportunities in the real world than in the special disability world. This comment may seem a little strong - but the more people we are around, the more people there are to learn from and be supported by. The special world can't compete.

10. Having a career

Initially I was going to say "employment" but the truth is, I enjoy having a career. I am a freelance journalist, as opportunities arise, I adapt and take them. I now have a community of fellow journalists and friends. They support me in causes that are close to my heart. It's an inclusive life.

My mum set me on an inclusive path and now it is up to me to maintain this lifestyle. I ensure any paid support in my life supports my natural unpaid support. I fight for my legal right to partake in all aspects of my community. This is vital. Being present is simply not enough; it is about really being immersed in the different communities, known by many, taking part. My advice is to think generic not disability world. Successful advocacy for me is living among my journalist and other regular communities. As much as I love the disability advocacy community, people with disability have needs outside this disability space.

I am a firm believer that this world – inclusion - is possible for all.

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