

Connecting beyond words

By Brian Procopis

Alexander Procopis and Joe Surawski both have Down syndrome and autism. They were 12 years old when they met at Aspley Special School in January 2010.

Alex doesn't use spoken language to communicate. He is introverted and very quiet. When in large groups of people, he will retreat to the corners and finds it very difficult to engage. As his parents we knew that Alex would need some assistance to find and maintain friends, but we knew that those relationships would be important and necessary for him.

We asked Alex's teacher Brad Morse to 'keep an eye out' for any spark or chemistry that appeared between him and any of the other students – a spark that could potentially ignite the beginning of a friendship.

Three weeks into the school term, Brad had some information to share. He'd noticed one of the class members Joe mischievously and silently relocating Alex's water bottle to his own desk. Alex responded swiftly; he quietly shifted his chair backwards, walked to the culprit's desk and defiantly took possession of Joe's pencil case.

Back in his own seat, Joe and Alex initially glared then smiled at each other.

From this initial spark, we set up a coffee meeting with Joe's parents followed by a couple of hang out sessions at each other's houses. In time this led to longer stays, then to sleepovers, holidays together and induction into each other's extended families.

The years passed, the boys grew, and their friendship strengthened. Before long the protective and predictable umbrella of school was over and other decisions needed to be made.

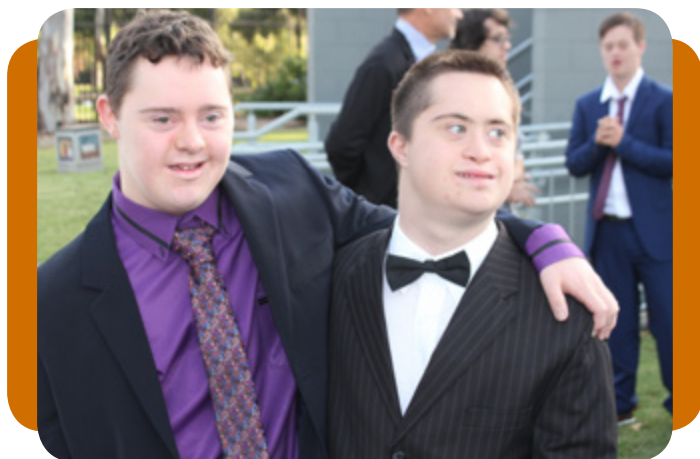
According to the late Jean Vanier, Canadian Catholic philosopher, theologian, humanitarian and founder of L'Arche, those with complex needs are not among us just to be looked after, clothed, fed and kept entertained. Their role is much more substantial and it's up to the rest of us to identify and celebrate their uniqueness, craft it where possible into a role, nurture it and allow it to blossom.

When this happens, we are all the beneficiaries.

Inspired by Jean Vanier's insights and together with Joe's parents, we set about designing a weekly program for Alex and Joe. We pooled their funding from Disability Services Queensland and recruited support staff that could resonate with our vision for them.

It was not necessary for the support staff to be experienced in, or familiar with, the world of disability; their qualification was their passion for what they did.

While Alex is introverted, Joe is more extroverted and helps Alex to engage more with his surroundings. Their very friendship has provided the tools for connecting at a level of significance with others as well. Alex and Joe are mostly 'in sync' with each other – but not always. Sometimes they get upset with each other. Whoever is with them assists them towards a resolution as well as an understanding of what is happening. They learn to be sensitive to the needs of all who share their lives.





Under the guidance of a support coordinator, we decided on a self-management approach and developed a weekly program with specific attention to the needs and strengths of both boys.

Their week includes physical activities such as sport and working out at the gym. The focus is on enjoying the activities and valuing the company of one another – teamwork. The hope is that friendships will flourish within an environment of health and fitness.

When asked ‘What do the boys do for you?’ gym instructor/personal trainer Michael replied without hesitation:

‘I work in gymnasiums amongst the mirrors, furtive glances and desires to impress. Gyms are of course more than that too. I love this world but sometimes I need to be saved from it. Along come the boys with their willingness to work and have fun in the ego-free zone that they represent. In doing this, they remind me to be honest with others and especially with myself.’

We also focus on academic, skill development and employment options, but an important part of the boys’ lives has been coming together through music and art. Music is the language of the heart. On Mondays, vocalist/multi-instrumentalist Dale arrives at our home with his box of instruments – guitars, harmonicas, percussion and ukuleles. Fortunately, there is a piano already here. For two hours, Dale and the boys have a jam session. They are participants in music-making not just audience members.

The boys are also a part of Screech Theatre where they learn to act out roles which highlight specific feelings and emotions within an atmosphere of fun and creativity. The boys are natural comedians – not surprising considering the ‘spark’ which drew them together in the first place. Their love of teasing each other (and others) and responding with mock indignation when on the receiving end is being fine tuned by their Screech Theatre coaches. They also sing with the Sweet Freedom Singers – a street choir which is home to an enthusiastic collective of people who like to sing but find it hard to fit into more conventional groupings.

The NDIS enabled us to recruit two support workers, Tienielle and Kirby, two young mums who developed an instant rapport with the boys at the gym. Neither of them are qualified disability support workers, but they have their own repertoire of skills and experience. The decision to harness their passion and creativity has been vindicated many times over. They are younger, more energised and far ‘cooler’ than us parents. Importantly, their presence in the boys’ lives softens our anxieties over that perennial and agonising question ‘*What happens when we are no longer able to be so actively involved?*’ Tienielle and Kirby take the boys to their therapy sessions ensuring that lessons learnt are communicated and practised within the boys’ growing network. One Friday evening per month, the boys attend a supervised disco where they are able to demonstrate their carefully rehearsed moves, meet new potential friends and have a laugh.



These activities and excursions out together have helped Alex and Joe manage situations that have been difficult for them previously. Fear of crowds, noise, heights and new experiences in general are becoming less intense.

Familiarity with other participants will hopefully lead to further friendships and opportunities to get together outside of the planned activity.

However, it was during the Access Arts program Grounded in Rhythm, under the skilled tuition of Zimbabwean musician Tichawona Noble Mashawa and acclaimed vocalist/drummer Velvet Pesu, that we discovered a remarkable talent in Alex.

Beginnings are often unexpected and comprehensible only in retrospect. At a birthday party of a friend turning 70, each person had an opportunity to voice a memory and Alex, the youngest guest, claimed his space. Nobody expected him to speak, not even us. But speak he did – in his own mysterious language.

Even after many years of speech therapy, Alex doesn't choose words. He does however sing. He sings in a language none of us understand – it's deep, rumbling and mysteriously reminiscent of Tom Waits and Leonard Cohen.

When Tichawona heard Alex sing for the first time, he was amazed and noted 'If Alex had been brought up in Zimbabwe, he'd have been chosen as a potential elephant whisperer'.

Alex's words were indecipherable, his melodies indeterminate but his vibrational bass vocals were similar, according to Tich, to the communications between elephants.

Alex became known as 'the elephant whisperer' and has been featured in various newspaper articles. He went on to perform at the Undercover Artist Festival and Woodford Folk Music Festival with Tich and Velvet. He had a new identity, a swagger and a sense that he was contributing something of value. In his audiences were people of power – politicians, departmental and organisational senior staff etc – all silenced as Alex would sing. It was a role reversal as Alex claimed his place as a unique performer.



Alex has gone on to record a mini symphony with Tich and Velvet which can be found on YouTube (*Alex and the Elephants*). The recording *Giant Hearts* has been sent to elephant sanctuaries across the world. Invitations to perform to the elephants have subsequently come from Nairobi, France, the USA (Tennessee) and Melbourne.

Joe's talents have also blossomed in this appreciative environment. He's a dancer, a singer and co-writer of *Rock and Roll Band* and *Sing the Opera*. With ease and style, he takes the microphone and becomes the confident MC to the delight of all within earshot.

We are feeling our way. We recognise that others do it differently – probably at times more effectively. But capacities and needs are different as well. We feel no need to compete. We know that their circle of friends needs to expand. We are working on this.

The boys are healthy, friendly and laugh often. We see this as a barometer of sorts indicating a convergence of positive things.

They help us to be elastic, creative and questioning of conventional paradigms.

Of course, we have our concerns and sleepless nights. We know about vulnerability. We also know that we won't be around forever. We need to equip them as best we can for this eventual scenario.

In the meantime, we work towards our goal – a productive and happy life where our precious boys love deeply and are loved in return.

Brian Procopis is Alex's father and is from Brisbane.

See the musical talents of Alex and Joe under this issue on the Voice website. www.downsyndromevoice.org.au

