Max's Story

Max's story was compiled after interviewing Max's mother B-J; observing Max in his school environment; gathering contribution from Deb, his classroom teacher, and; talking with Pete, the school support officer who works with Max three days a week.

Introducing Max

Max is a seven year old boy who lives with severe dystonic Cerebral Palsy. Max uses non-verbal communication, specifically his eyes as pointers and facial cues, and uses a wheelchair for mobility. Max lives with his parents B-J and Tim, and his baby brother, Quin. He is happy and interactive and clearly a valued member of the family. He has been attending a mainstream school for two years, where he is very involved in student life.

B-J speaks about Max

Kerry: What enables you and your husband to support Max to have a good life?

B-J: I think the love and commitment of people in his life. We have some help from an amazing Personal Support Worker, Zoe, who assists Max to get ready for school and spends time with him after school for an hour. It makes a huge difference having everybody, including family, support workers, teachers, health and allied health workers, and Max working together as a team.

Quality of life for Max is about having fun, it's being listened to, or having his opinion or his ideas expressed and heard, or having options and choices. Quality of life for Max has also meant managing serious health issues.

His determination and that of the rest of us to move beyond the disability is really important. So is the separation of him 'the person' from Cerebral Palsy 'the condition'. It is the very least of who he is. If anything, his disability has provided us an insight into his character that we may have otherwise not seen. The extent of his strength, willpower and courage are highlighted in his management of the barriers he faces.

These things as well as the normalisation, wherever possible, of him as a seven year old boy enable us to support Max to have a good life. When he was only a few months old, I blue-tacked a note to the fridge "We have a choice – we can allow Cerebral Palsy to devastate or to enrich our lives." As parents we made a commitment to support Max's interests and goals; his hopes and dreams. And so what we've done is look at what his interests are, supported those, and refused to be pulled around by the nose by the disability.

In order to ensure Max has a chance at a good life has also meant challenging inherent social and policy barriers. Through committee participation, letter writing, and sometimes political involvement, we have tackled discrimination, social policy and other barriers to rights, for example to access a bus for excursions, to access Out of Hours School Care, adequate computer supports to access the school curriculum – even access to basic equipment when it is urgently needed. Without the positive outcomes from these campaigns our son would not have quality of life.

Kerry: What do you see as the impact on the family?

B-J: I think it's hard work. Cerebral Palsy makes great demands. It's got a life of its own – it's a separate entity with physical and emotional demands. Physically it's very hard in terms of lifting and moving. Our son needs assistance in every aspect of life. Although once he is set-up for games on his computer, with all his limb-supports and switches – he's off and away.

Max also faces barriers of communication and we're all affected by that because he's got opinions and ideas but it's really hard to make them known. It's frustrating because there is some ignorance around disability, particularly when a person is without speech. There's a presumption that when someone doesn't speak and can't move they are cognitively impaired, but he's not - he's been able to function in a mainstream school despite the barriers.

But a lot of people will treat him as if he doesn't know the first thing about anything. So that's really frustrating. We, as a family, have to battle myths, judgments and assumptions. Even within our own extended family we find it really hard to engage people to get to know Max. The social isolation Max deals with because of his disability is sometimes really hard to witness and manage.

As a family we feel like we're always vigilant and on the watch-out for Max. You can't go somewhere and just switch off and relax and become part of that community of people. You're always assessing the situation and so is Max. Max is looking around, thinking "Well, you know, where do I fit in this situation, or where's my place?"

We try not to shy away from those situations. We certainly take him out to events and venues etcetera, but it does have an emotional cost as a family, and you think, "Oh … how do we tackle this?"

Kerry: Do you think this impacts upon your relationship with your partner?

B-J: Tim and I have got a good relationship, we always had that, and we've been able to rely on that. Having a child with a disability can be a strain on a relationship, but I think so are many, many other things. I think the important thing is being aware that you're under strain, but I guess it's also doing whatever you can as a family, or as a couple, to nurture yourselves, your partner and your relationship.

I think if one person in the relationship fears the disability or is ashamed of it and the other is person's not, then it makes it really hard, but if you're both on the same page it is easier. Tim and I are certainly on the same page. We focus on our kids and we focus on each other. We are very proud of our kids and with disability; we don't have a deficit approach. We see it as an experience of life rather than doom.

Fortunately we have support from our parents and they are a big part of Max's life, we also have good friends who understand the issues and what the needs are, and are very positive in their approach. We both have a spiritual faith. We're not overly religious, but we go once a month to an Anglican Church Children's Service headed by wonderful, zany Reverend Mara and that's a strength.

It's almost like we've been handed something amazing to watch. In some ways Max is miraculous in our eyes, just to see Max go from such terrible situations to doing the things that he's doing, we're really proud and really joyous. We look forward to what he's going to do next. He keeps us buoyant. Max is a great kid. I think that helps us. We're lucky to have a precious kid like him and baby brother Quinlan is shaping up to be quite a character too.

Kerry: Are there any suggestions you would make to others in a similar situation?

B-J: There's a lot of personal things like having a belief in the child; a belief in yourself, your own strength and courage. The willingness to take a bit of a risk, to problem solve barriers can pay off as well. Being prepared to step out of your comfort zone is useful. The ability to ask for help, get the information you need and to really push some boundaries is important.

To maintain a positive focus - it's not expecting miracles, but it’s the ability to aim high and find the best in the low situations. Setting goals but at the same time not wrapping your quality of life in the sense that you have to achieve those goals in order to be happy. It's about having an optimistic frame of reference.

Being flexible and trying not to close the door on possibilities, especially with a child. It’s important to be really open to whatever happens and what evolves. Just because a person’s life has impediments doesn’t mean that it’s not going to be a successful life or a wonderful life. Using humor and ‘letting your hair down’ once in a while is good too.

Kerry: What has been helpful to Max in his journey?

B-J: When Max was young I made a book of wonderful, real-life, stories, collected from around the world about people who faced disability. And it’s not to say that they were cured, these people still have or had significant disability. These stories are about what they did with their disability. It’s just like the 100 Leaders Project. That’s why I think it’s such a valuable project because it looks at what people have done successfully while living with a disability.

Max has got posters of role models on his wall; boccia players who have cerebral palsy, and I think that has helped him look at disability in a positive way.

A few weeks before Max was born I was home and it was ironic that the Paralympics were on at the same time. I remember thinking, “My goodness, these people are real heroes, not only are they international athletes within their sport, but are facing significant other barriers. They don’t have the sponsorship, they don’t have the support or recognition that mainstream Olympians have,” and I just was gob-smacked by what I was seeing.

Paralympics is only one avenue whereby people can push beyond their disability, and how far they move or where they move should always be kept open. For our child we keep that door completely open for possibilities, without having expectations. What Max has to cope with is very hard and frustrating, and I think a lot of people look at him and think, “How will you manage that?” and “How horrible!”

We look forward, with hope, to what Max might do with these huge challenges, what he can teach other people and what he can learn from his experience as well.

Kerry: What about school?

B-J: When Max was in kindy I interviewed about 12 schools. It was a real journey. We heard some really discriminatory reasons why Max would not benefit from being part of a mainstream school. Yet there were a couple of schools that were the opposite.

One Catholic boy’s school said they would be privileged to have Max attend the school. They said, “To be honest, this would be the biggest challenge the school’s ever faced in terms of a student’s needs, but we’ll meet it head-on, and we’ll try and get as much fundraising happening as we can.” After some of the negative experiences, we were so pleased to hear this.

The government school we eventually chose for Max shared a similar philosophy. It is a school shaped by past students living with physical disability. People become aware and they learn from a person living with disability. If children with disabilities are not attending mainstream schools, if they are squirreled away and hidden in ‘Special Schools’ then it’s difficult to gain awareness and inclusion.

A severe physical disability doesn’t mean a child cannot learn. It just presents a challenge to the mainstream schools. How to teach a child with these needs? Max is fortunate to have incredible school support officers and a great teacher who has been keen to pioneer this challenge.

The Deputy Principal sent me an email, a year or so ago, I kept it – it said:

> “*The more effort a school makes to include and welcome students with disabilities, the even greater reward for the school itself. I have watched the way students interact with Max and (name of another boy with similar disability) with interest. They are not interactions of pity, nor attention seeking, but rather a genuine liking and welcome as a class member.”*

We’ve also heard from parents who come up and say, “My child was really thrilled to have Max in his/her class, and has learnt so many things.”

Max is really valued by his teacher and the school support officers that work with him**.** They know how to get the best out of him. If we tried to do some of the teaching activities that Pete does with him at home, it just doesn’t work, and Deb, his teacher has a most powerful influence on Max. For him, there’s no-one like her. She can look at him in a certain way and he responds.

In the first or second week of him attending school Deb sent him off to the office after two warnings and I thought, “Oh, goodness me, what’s going to happen here with these two?” He quickly learnt that she means business. Yes, he has a ‘big’ disability but he’s there to learn! To get him to do his homework I’ve tried to emulate her, I’ve tried to act like her, use her words, but it doesn’t work.

Tim and I were initially hesitant to believe he would be able to learn at school. Yet at the end of year one, we were being told he understood the difference between adjectives, verbs and nouns. I remember thinking, “What! You’ve got to be joking.” So Zoe, Max’s personal support worker and I tested him that afternoon. I asked him to ‘eye-gaze’ a verb out of a group of adjectives. And he did. And I just thought, “Oh, my goodness, how did that happen, how did that evolve, how did he learn that?”

Visiting Max at the school

A visit to Max one morning at the school he attends opens one’s eyes to his personality and his intelligence. Max makes his wishes, likes and dislikes, and choices known in the classroom. He communicates in subtle and not-so subtle ways, the classroom teacher and school support officers are familiar and skilled in interpreting his particular wishes, choices and preferences.

Max is very social. It is obvious that Max is well liked by other students who respond positively to him. Max works closely with his school support officer, Pete. Pete and Max have an obvious close bond. Pete describes Max as a 'can-do' person. He is willing to have a go at new things and it is obvious that he enjoys engaging with the learning program.

Pete showed me evidence of the work Max has been achieving in relation to English grammar. He has been constructing sentences and clearly demonstrating an understanding of grammar. His level of sentence construction and demonstrated comprehension is excellent. Pete informs me that Max has improved a lot over the last six months of school.

It is clear that Max enjoys being part of the class. He becomes disgruntled when he is not positioned to attend to the teacher and take part in class activities. He persists with being disgruntled until a school support officer positions him to face the teacher. He is completely focused on the teacher and follows her with his eyes. Following instructions from the teacher and working one-on-one with a school support officer Max takes part in an activity making his selection of colours known.

He recently finished a term of being on the Student Representative Council and, according to Pete, has fulfilled this role well. Max is now improving his physical fitness and walks with a walking aid for periods each day. It is obvious that attending school is important to Max and provides him with an improved quality of life.

Deb's perspective:

Deb is confident that Max’s disability will become less conspicuous as he moves through year levels. He is a student who has goals; he is engaged in learning and has a strong sense of self and sees himself as a contributing member of a wider community. She believes that what limits Max is access! His desire to communicate at every level of his life and to discover for himself the answers to his questions is limited only by technology.

In a world that moves so fast through technology this is extremely frustrating from her point of view. As a teacher, Deb encourages her students to have a voice. This allows students to develop skills; knowledge and values that will help them become valuable members of our society. It’s a testament to Max, given his limitations; he makes sure he is heard, understood and contributes at the highest level of his ability.

Deb looks forward to the day she receives her first communication from Max that has been completely constructed by him. This will truly be a day of celebration!

The school makes every effort to be socially inclusive of children living with disability. In the classroom, efforts are made to ensure Max experiences everything the other students’ experience. Being able to think quickly is important to ensure activities can be modified so that Max is included in the school program. For example, when they are skipping with the big rope Pete makes sure Max is going through the rope in his wheelchair.

Max particularly loves being outside and participating in physical activities. When the other kids stop to have recess he has his fruit and yoghurt. Most importantly it is clear that there is respect for Max as a member of the class.

Max attending the vacation program

Max attended seven days of the vacation program (both centre based and excursions) which included travelling by bus to destinations with his friends. Not only did he attend the excursions, he was involved in all activities, including swimming. He had the opportunity to enjoy the vacation program experience along with his fellow students.

Max spends quality time out of his chair where he enjoys watching TV and having stories read to him by his peers (as they lie on the floor together). In his walker he has the opportunity to weight bear and the freedom to move around in the gym and participate in all games.

Pete says having the opportunity to observe how Max is included as part of the wider group at school is wonderful. It is great to see his peers spend quality time with him and make him feel welcome, valued and special for the person he is.