

Finding the pathway to an inclusive life through vision and valued roles

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My son Gerard is in year 7 at his local high school. He's a happy and sociable boy who loves music, watching movies (he's a big fan of *Harry Potter* and *Lord of the Rings* – particularly the noisy and gruesome battle scenes) and he really loves school.

His favourite food is chocolate – particularly the Easter egg kind and he loves swimming. If anyone has been to the pool in Guyra, you would discover a new meaning to the word 'heated' (not!) but Gerard can outlast most of the other boys and will stay in until his teeth are chattering. But his favourite thing of all is football. Gerard is a supporter of Parramatta Football Club and no one gets to watch a movie on Friday night if he knows the footie is on!

But in addition to all this, Gerard was diagnosed at birth with profound multiple physical and intellectual disability – a genetic disorder known as Wolf-Hirschhorn syndrome. He required immediate surgery and a number of follow up operations and so the first 18 months of his life were spent either going to or coming from hospital. We were so frantic during this time that we could see no further ahead than the next hospital visit and some days it was nothing more than just hoping that he would be alive the next morning.

In between visits to hospital, we were also involved with the Department of Aging Disability and Home Care, Early Intervention and Vision Australia for intensive therapy. In these early days, professionals – including early intervention professionals, played a big part in our lives. While we had wonderful and supportive staff running these programs, the 'therapy scene' seemed to be all about identifying the very many things that Gerard couldn't do and working out how to 'fix' them.

While this is necessary and in fact essential for our kids, one of the unintended side effects is that families can get bogged down in the negatives – just looking at all the things that are seen as 'wrong' with your child and it's then easy to lose sight of who they are as unique individuals.

During this time we became aware of the typical life path traditionally followed by people with disability – early intervention, special school or class, sheltered workshop, group home, day program – and this filled us with despair. Even though our communities have become more accepting of people with disability, it still seemed to us that people with disability were being set aside, in environments that were touted to be safe, but where they were grouped together not on factors of age or common interests. The only common factor was their disability.

They seemed to do activities that were chosen for them by other people, housemates chosen by a selection panel, etc. It seemed to us a life of waiting, of just filling in time with very little happening about whom they were as individuals, or what gifts they may have to bring.

In these dark days, it would have been a liberating and affirming thing to have been encouraged to think about a positive future. To be encouraged to have dreams for Gerard in the same way that we did for our two older kids.

Fortunately, when Gerard was nearly two and we were no longer traveling to Sydney Children's Hospital on such an intensive basis, we had some space to look a little further ahead than just tomorrow. Although most of what we imagined in Gerard's future was frightening, we forced ourselves to face some of it and started to make some plans.

I started attending workshops and information sessions and travelled considerable kilometres in this process. One of the workshops I attended was called Inclusive Lives. Parents of children with disability talked about a very different vision they had for the future. Children catching the regular school bus, attending their local school in the mainstream class, growing up and owning a home, owning a car, having some sort of meaningful work situation, or following leisure interests and activities that they had chosen themselves.

These parents were imagining lives of belonging, of worth, of having real relationships and very real places in our communities. It was very different from the traditional path for people with disabilities that I had come to accept as inevitable for Gerard. My first reaction was that this was a whole load of 'pie in the sky', that 'these people were in denial, they just needed to get a grip, accept the fact that their child is disabled and just get on with it!'. Not only was I challenged by these ideas but I was also very angry.

It seemed to me that there was a line in the sand. I could see that kids with mild and moderate support needs were on one side of the line and might be able to live a more 'normal' life but I couldn't imagine that kids with high support needs could achieve any of these dreams and I knew that we were on the wrong side of the line.

Trying to imagine just what Gerard would do in the regular class of his local school was almost impossible, let alone imagining him having a regular job or his own home. It seemed to me to be some sort of bad joke.

But at the same time that I was indulging in a bit of a pity party, I couldn't let the idea go. Just what if this could happen for my son, what if he could have a real life instead of just an existence, real friends instead of just paid workers? Wouldn't it be worth checking it out? And whatever way I looked at it, the answer was yes. And so we began a slow and almost reluctant process of finding out more. Attending different workshops and reading any information that we could find. By the time Gerard was three we knew that we were no longer going to accept the traditional path for people with disability for our son. We wanted something better. We started to believe that he could have a real and meaningful life and we were ready for action!

Given Gerard's age, our action started in thinking about where Gerard would spend his time before he started school. During this time, the message we were getting and the assumption people were making about kids with disabilities – particularly those with high support needs – was that they would go to a special setting – a support class or special school. The information made readily available was about these special options – not ordinary ones. These weren't even put forward as a possibility. It was difficult for us to insist that we had decided against these special settings and were choosing a mainstream option for Gerard, but insist we did. Once it was obvious we wouldn't be swayed from this choice, Gerard's support team were 100% behind us and worked hard with us to make it a success.

With the support of our early intervention teacher, we approached the local Guyra Preschool and Long Day Care Centre to enroll Gerard. After a number of phone conversations, I met with the director. She looked me in the eye and said; 'well, we're absolutely terrified, we've never had anyone with a disability before but we want to give it a go'. The first day of preschool, I sat by the phone waiting for them to ring to say they weren't coping and could I come to collect him. But the call never came. It was the first day of two wonderful years. The preschool went on to win a statewide inclusion award for their work with Gerard and another student with a disability that enrolled at the centre in the following year.

Throughout Gerard's time as a pre-school student, the early intervention teacher worked with the pre-school so that Gerard could be well supported and included. About half way through Gerard's first year at preschool we began to plan for his enrolment in primary school. The early intervention teacher was part of this process too.

There was still pressure at this point to rethink our choice and choose a special setting for primary school. There was pressure about his 'readiness' about whether he had the necessary skills to cope with kindergarten. As far as we were concerned, there was only one 'readiness' test – he was breathing! Having ticked this box, we attended more workshops and undertook further research to understand better what support would be needed for Gerard to be successfully included in the mainstream class of his local school. One thing that continues to astound me to this day is that all the research we could find comes to the same conclusion – that kids with disabilities are better off both socially and academically if they are educated in the mainstream class of their local school, rather than in a separate class or school. Kids without disabilities also benefited from kids with disabilities being included in their classes. So we knew we were on the right track.

We created a book about Gerard using lots of photographs to show what he had achieved at preschool and then used this book to introduce Gerard to the principals of both our local state school and the Catholic school. These meetings took place approximately fifteen months before Gerard was due to start in kindergarten, so we felt we were giving them plenty of notice. We then arranged for them to meet Gerard at the preschool rather than at a boring meeting where he would not sit happily in his wheelchair for very long.

As our other children were already at the Catholic school, we really hoped that Gerard could go to school with them. However, we knew that funding for the support Gerard would need differed greatly from what was available in the state system. So we were pretty much expecting a knock back.

In December 2002, just before Christmas, we received a phone call from the Special Needs Co-ordinator from Catholic Education and to our amazement and absolute delight we were told that they were looking forward to Gerard joining the school for kindergarten. So Gerard became a Kindergarten student in February 2004 with other kids from our church and preschool and, most importantly, with his big brother and sister.

I think back sometimes to the year before Gerard started school and remember what a hectic time it was. There were many planning meetings. Each of the myriad of professionals had goals for Gerard. How could he hold a pencil? How could he learn to sit unsupported, etc? But I had

only one goal, which I was too afraid to even write down, let alone speak it aloud to someone. It wasn't about what he could do. It was about him belonging, about there being other kids who cared about him.

How is this acceptance demonstrated by kids? It is demonstrated by an invitation to a birthday party and that is what I longed for Gerard.

I didn't want just any old invitation where the parents insisted that he be invited – I wanted a child to want him there. Because a party invitation is the 'badge of belonging' when you're in kindergarten – that's the acid test!

Gerard had been attending school for about four weeks and one Thursday morning I was wheeling him through the car park, when I heard a child come running up behind me. I heard her excited voice – it was Hope, one of Gerard's classmates. She was talking to Ben, one of the other kids. 'Ben! I'm turning five and I'm having a party, here's your invitation!' Well, my heart just stopped and I quickly pushed Gerard up to where the teacher's aide was waiting and engaged her in conversation so that I could ignore the excitement going on around us and avoid the pain of knowing that Gerard was probably overlooked. But a few moments later Hope was running up to Gerard, grabbing his hand and shaking it like crazy and yelling 'Gerard! Gerard! Guess what? You're coming to my party! You're coming to my party!'

We'd done it! For that precious moment he really belonged. Gerard was just another kindy kid on his way to his first birthday party.

Now that he's a high school student it's a different gig. He hangs with the other boys before school and gets the 'goss'. Gerard's a great mate to have because he'll never betray a confidence! And the boys fight over who gets to take him across the oval to the 'ag' plot - doing wheelies and donuts is a blast, particularly when it's muddy!

It's these kinds of experiences that continue to reinforce the value of the choices we have made. Our vision – informed by our continuing self education – has continued to drive our actions around Gerard. We envisaged him as being a valued, accepted and respected member of his local community and, little by little, this is coming into being.

An important step in achieving this was learning from other families about the benefits that having ordinary, valued roles could bring to Gerard.

Gerard is a student but he is also a swimmer, a football fan, a church member, as well as many other roles – including, of course, a birthday party host.

Each of these roles has played a part in changing people's perceptions about what could be possible for Gerard and who Gerard is. They have added to Gerard's opportunity to interact with others and to increase his skills. They have also impacted on Gerard's sense of who he is.

Like the rest of us, the more roles that Gerard has around things of interest to him, the more likely he is to come into contact with people who may forge more lasting ties. These people could be a potential future housemate, or maybe even his friend. After all, most of us meet our partners, get our first job or find out about an opportunity – through our roles.

I will share a little more about one of Gerard's roles to give you a better idea of what I am talking about. I have already mentioned that Gerard has significant support needs. When I first came across the concept of deliberately creating roles for people with disability I was excited, because I knew that, particularly as he gets older, Gerard is at risk of becoming isolated and having few people in his life. However, it was difficult to think of a role that Gerard could undertake because all the roles I could think of required some degree of physical skill and these are not Gerard's strengths.

At about this time we became aware that Gerard loved watching rugby league. He cannot speak but was clearly cross when the football was interrupted and he was happiest when Parramatta was winning.

So we began to think about the possibility of Gerard taking on the role of Parramatta Football Club Supporter. We helped him save his pocket money to purchase a jersey, beanie, scarf and cap. He wears the clothing during football season and goes to places where other people like football, which is pretty much everywhere in our local community! The most important thing about the role is that it didn't involve a lot of physical skills – just being there and cheering!

With Gerard in the football gear, people's reaction to him changed instantly. Rather than ignoring Gerard, people – particularly those who follow football – came up to him and talked to him about the football. Even though they could tell beforehand he would not be able to speak back to them. They no longer see him as defined by his disability but as a boy with individual interests that reflect theirs. This has given Gerard more social interactions, more opportunities to practice eye contact and interacting with others and an opportunity to be better known in his community.

As I said, Gerard is only thirteen and in year 7 and who knows where this will lead. It is just a simple example of the way a role can impact.

Even with a vision, planning and positive roles I think it's important to say at this point that sometimes the wheels do fall off in school and in life. Things aren't always perfect. There are often times in the school day when Gerard is not able to be involved. There are interactions that are fleeting. There are parties he doesn't get invited to. Gerard still has very significant support needs. Yet, even with these imperfections, the benefits of having a focus on him being a part of the ordinary flow of mainstream life have been amazing and Gerard has achieved so many things that we never thought possible.



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