

Warren's Story: A Meaningful Life

"This story is told respectfully from my viewpoint as a mother."

Anita O'Brien

There is an old Hasidic saying: "God created people because God loves stories."

Stories sometimes sober, sometimes instruct, and often can give us hope for something better. They often ask us to face facts in people's lives that challenge some comfortable beliefs. However, it is important to tell the stories to realise we all share similar struggles, and can encourage each other with the successes towards a more meaningful life. In this story you will hear how dreams became reality, and how community is better than segregation.

When our children are born we are given a book with no title, a book saying; "Please read me! Don't write my story for me!" We have dreams for them and they develop their own dreams, of a meaningful life, of making a difference in the lives of others, lived in the shelter and encouragement of others. Wholeness and wellness in body, mind and spirit! When our younger son was born we had dreams for his life, and we would love, protect, encourage, and support him in his life's journey.

However, Warren was slow to develop, to sit and then to walk, and it wasn't until he was almost three that we were presented with the diagnosis of cerebral palsy. We knew nothing of the world of disability, but of course were still determined to give him opportunities to be the best he could be, just as we did for his brother. We were to rely on the professionals, as they knew best, whilst still pushing the boundaries. I did not realise what that would mean for the next thirty years of Warren's life. This story will focus more on the last five years of his life and I will leave the earlier years for another day, or another book.

We live in the shelter of each other! I liken this to a tree in full bloom providing beauty, protection and shelter from the storms that sometimes surround us; winter may come and the leaves may fall, but the branches remain, bud and bloom again and the roots go deep. Without people who know us, spend time with us, become our friends, our life is not only lonely but also vulnerable. Segregated, away from community, we don't have the opportunity to give and receive friendship and build relationships, or to grow the branches and build the connections that add richness to our lives and keep us safe.

In his book *From Brokenness to Community*, Jean Vanier expresses his belief that community is a place of struggle and sometimes of conflict, but also it is a place of celebration, joy and ultimately, of human fulfilment. Treasures in the cabinets of our home contain many different memories and represent the beautiful tapestry of a variety of different relationships and experiences. Photos of family and friends

remind me of the richness of my life through friendships. If you look underneath the tapestry you would see threads going in all directions, intertwined with each other. Whilst there are silver threads of laughter, there are also tears, heartache, and sorrow; challenges, achievements, failures, and ordinariness.

It is usually in this ordinariness of life where we interact with many different people, through work and leisure, social occasions, community events and activities, and family gatherings, that we naturally develop relationships with people—some who become friends, others workmates, perhaps a team member or a person with similar creative interest in a community group. All this and more, is typical human experience. In our community we interact with many different people and develop relationships and friendships that bring colour and add diversity, richness and meaning to our lives.

What happens when we limit the opportunities for people to experience the richness that life can bring, even with its ups and downs, often denying them the opportunity for a meaningful life? Only when individuals with a disability are present in community, living life in a normative, every-day citizen kind of way, does community grow in its understanding, change its attitudes and value the contribution that people with disabilities offer.

This story is told respectfully from my viewpoint as a mother; it is Warren who lives his life, walking a road with obstacles, barriers and often with many frustrations. I am so proud of him for his cheerful outlook on life and for what he has achieved. I am constantly learning from him.

Warren is now in his mid-thirties. He has a good sense of humour and a strong sense of justice. He is caring—especially of the elderly and those in trouble—a music lover, has a sensitive spirit and loves his church fellowship; he also loves to socialise and drink cappuccinos. His passion is his interest in the police and their work.

Warren has spent much of his life in segregated settings, and in his late twenties lived in a group home for three years away from the community he grew up in, as well as attending an Adult Training Support Service in that area. Warren does not need 24-hour support, in fact much less, but does require support that is focused on his individual needs. Whilst we were grateful for the welcoming and caring people providing assistance in the group home, being in a congregated disability setting most of the time was dragging him down and he was increasingly anxious. Warren was missing his 'home community' and knew there was something better. So, until five years ago, his life was controlled by services and systems to a large degree. We thought that was the only way.

In early 2000 I attended a seminar by Michael Kendrick and both my heart and mind agreed, but I wasn't sure how to achieve the dream of assisting our son to have his

own life and not one dictated to by systems in traditional settings. At the same time, Deb Rouget of [Personalised Lifestyle Assistance](#) (PLA) was encouraging parents to dream of something better. It was not until 2005 after attending a seminar in which the parents of the Canadian accommodation and lifestyle model *Deohaeko* presented their story, did I see the exciting possibilities. I was inspired by many people who had made substantial ground in supporting people with disabilities to pursue their dreams and have similar opportunities that most people take for granted—to live in one's own place, work, recreate and make genuine friendships in the community.

I realised that it was “more painful to remain in the bud than it was to blossom”. The light was burning into my mind that Warren could have something different, that it was okay as a mother to think positively and have dreams for him, just like I did for his brother; validation of my feelings was empowering. I had always desired for others to see Warren for the person he is and for what he can offer others rather than see his disability.

Over the last few years I have been learning to hold on in a different way to allow Warren the opportunity for growth, to develop new abilities, tackle challenges, increase in confidence and articulate his dreams. The last five years have seen an amazing transformation in his life from segregation to community.

When we started on the journey to a more meaningful life for Warren we did so without funding for support; however, whilst we needed to be creative he did have freedom to choose. Eventually, we secured some individualised funding for support for Warren's volunteer work and some in-home support. But it wasn't just about the money; we had to be very creative for his life to be authentically real and not an artificial reflection of a typical life that is coloured by segregation and congregation of people with disabilities. Informal support is essential to everyone's life, so we also needed to think of community connections through work, leisure, social events and home life that gave the opportunity for Warren to develop relationships that would be natural and freely given.

Warren's family and friends/supporters came alongside in a *Circle of Friends* to assist Warren realise a vision for a typical life, to identify his interests and passions and to build a life that is typically lived in community. His vulnerability was a challenge, but we considered what was required for Warren to live his life of choice and thus find meaning and happiness. We believed in the dignity of risk as there is no such thing as a risk-free life, whilst ensuring adequate supports were in place. This insight helped us to appreciate the imposed constraints on Warren and motivated creative planning processes.

We have been supported by a service provider who acknowledges the authority of families to direct individualised funding and choose support workers. This has been empowering, and it has meant Warren's 'Personal Assistant' (as we call her) was

chosen by the family and has greatly enhanced Warren's life over the past five years. She is a great observer of people and the interactions that take place in differing environments, and applies that knowledge to enhance the opportunities for him. Warren has developed many friendships and relationships that may not have otherwise happened due to her skill in introduction, nurture, and withdrawing to allow the relationships to progress. She is also aware of that requirement when Warren is volunteering; "his work is his work", and only provides support when it is needed.

Warren has changed his roles in life and how he is seen by others; from client (90 percent of the time) to volunteer worker and artist—from group home to his own home. His interests and passions, skills and abilities influence the planning for meaningful days and his lifestyle of choice. Importantly, he has been realising his dream to work for the police—Warren is now a respected and valued volunteer worker for *St Vincent's Hospital*, *the Victorian Police Museum* and the *Salvos @Box Hill*, his church.

Through encouragement and support at *Arts Project* in Melbourne, he has established himself as an artist and is selling his work. Winning first prize at an art exhibition and seeing his art on a billboard in the community was a key moment in building his self-esteem. At a recent interview he introduced himself as "an artist": for us, that was a glimpse into realising that he is now seeing himself in a 'role', not just attending an activity. On another occasion, in response to a person not giving him the recognition he deserved, he said: "I work for the police you know!" New opportunities for work and leisure are regularly being offered through his established volunteer work and connections. He attends a local gym supported by a friend and this helps in his personal fitness and maintaining his health as well as providing the opportunity for new friendships.

By following a 'typical pathway' it was inevitable that he became an advocate for people with disabilities by his very presence in community, influencing attitudes for positive change. The initial challenge was to believe that it was possible for Warren to have a more meaningful, relevant and therefore better life. Each connection has often led to another connection, more work, experiences and opportunities. I am reminded that the most rewarding things you do in life are often the ones that look like they cannot be done.

As Warren becomes ever more known in his community, his vulnerability is reducing and his safety in community is increasing. Getting it right is a constant challenge, but all our lives are like that aren't they? It is part of being human. We remain focused on the identified values around Warren and ensure we continue to dream. As the journey progresses our experience is that possibilities that seem impossible can become realities.

Inclusion in community life that results in living a meaningful life of choice for people with disabilities has not only been a personal journey with our son Warren, but one I

share with many other families who do not want segregation and congregated care. An important part of our support was introduction to the family governed initiative [Living Distinctive Lives](#) (LDL), established by Personalised Lifestyle Assistance (PLA).

The experience of being part of a group of like-minded parents who have the same dreams for their sons and daughters is wonderful. We provide each other with much needed encouragement in times of struggle and disappointment, share our networks and ideas, get excited for each positive step—no matter how small—and celebrate together. Sharing in this way is like building your house on a rock and not on the sand.

Warren is weaving a new tapestry, metaphorically speaking, that shows achievements, struggles, and times of trying a different way; along the pathway there are heartaches, but also laughter and joyful surprises. He chose this way because, as he said at the start of the journey five years ago, “it is better”.

I am sure there is a far greater reason behind God’s intention for his creation than “God created people, because God loves stories”, however, it is a reality that as we share our stories we help each other in the journey of life. It is my prayer that as you read this story you will believe there is hope for the future both here and now, and in a place called Heaven, where all people shall be equal, loved and cherished. God shall wipe all tears from our eyes, and there will be perfect peace and contentment. In the meantime, you are what you choose today, not what you have chosen before!

Warren was featured in a story on the 7.30 Report, ABC Channel 2, which can be viewed by clicking on the following link:

<http://www.abc.net.au/7.30/content/2010/s2884121.htm>

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