

Planning To Achieve Insurmountable Goals

Josey McMahon is a mother of four adult children, step mother to two adult children, social worker and a passionate advocate for the rights of people with disability to have good lives that have meaning and purpose. She is also the twin of Cathy McMahon. From June 1967 to May 2014 Cathy resided in a large institution, isolated from family, friends and community. Through the tenacious efforts of her sister, Cathy is now living in a home of her own with paid and unpaid support around the corner for Josey and is putting her roots down in her local community.

In this article, Josey outlines the relationship between developing a vision and actioning the vision through strong intentional planning to achieve a good life for Cathy. She outlines the importance of holding the vision tight despite the challenges.

Cathy and I are twins and were born in the mid 1950's in a small country hospital in South West Queensland. We arrived 14 weeks premature and were not expected to live. However, due to both of us having great tenacity we survived the odds. It would appear that we acquired our disabilities at birth, possibly either too little or too much oxygen and very premature for that period of time.

We grew up in a large family with four brothers and three other sisters. Cathy remained living at home until the age of 12 years when it was decided she would be best cared for in an institution over an hour's drive from our family home in regional Queensland. Shamefully, she remained living there for the following 47 years. In May 2014 Cathy finally moved from the long stay institution to a home around the corner from where my husband and I live. We hope this is the start of a new chapter.

Less than seven years ago, moving Cathy into community from a long stay institution was no more than a dream in my mind. I wondered whether it would really be possible for Cathy to live in the community in a place that she could call 'home' and participate in 'ordinary' community life and be a 'valued, contributing member' of her local community. After all many people, including some professionals and family members, kept advising me that she was being well looked after and that she would never adjust to community living after being institutionalised for so many years.

In some ways this could have been an easier option for me to believe, however, deep down in my spirit I knew that this was not true. Cathy was being denied an opportunity to live a good life that had purpose and enjoyment for her. Instead, Cathy was living a life that was segregated, isolated from family and friends, sitting waiting, waiting and more waiting. She had no say over who she lived with, who supported her, what her daily routine would be. Why should Cathy be viewed as 'different', 'the other' and ultimately denied a life of purpose and left to live out her days in an institution where none of us would like to live?

I discussed my dream of Cathy living in the community with so many people – my husband, brothers, sisters, friends, allies, advocates, community workers, bureaucrats, ministers as if it might happen by just talking about it. So many people had heard my story over the years. When I reflect back there were many wasted hours in just talking and not doing. In the late 1990's some friends, my sister Carmel and I participated in a planning session with a work colleague acting as the facilitator. On reflection, although it was a great planning session what stopped me from going forward was my lack of belief that my dream and vision for Cathy could become a reality.

How did I turn the dream into reality? The turning point for me firstly, was to believe that Cathy deserved and had a right to have a good life that had purpose for her - a life that was crafted to give

her great fulfilment and enjoyment - a life very different to the past 47 years. Secondly, I needed to believe myself that this was possible. There was no use riding on the backs of someone else's beliefs that my dream was possible. I had to 'own' the dream and vision for a good life for Cathy if I was going to be the person to drive it forward and I had to be the person to drive it forward as there was no one else in the driver's seat. *If the dream was to be it was up to me to make it happen.* For it to become a reality I had to focus and remain positive about what I believed and not allow distractions and negativity from others to get in the way. I had to have a shift in my thinking from 'things happen to Cathy' to intentionally making positive things happen for Cathy. I had to be that strong tenacious advocate that I was for so many other people with disability.

I also struggled with the notion of doing it all myself and I knew that it wouldn't happen unless I had a group of like-minded people around me who would walk the journey with me. It was difficult for me to ask people to be part of a circle of support, however, when I approached people and asked them to be a member of the support circle for Cathy people have responded very favourably.

The attendance at a six day workshop in 2007 gave me, Carmel and a small group of friends who had met and got to know Cathy an opportunity to think thoughtfully and respectfully about what a 'good life' would look like for her. It was here that I was also challenged to think about Cathy as a woman in her own right rather than a severely disabled woman. It was very important for me to be clear about my own values and beliefs about the place of people with disability, about the gifts and talents they bring and the contribution they can make to community. In this instance I needed to be clear that Cathy was no different to other people. Similarly, despite all those years in the institution she was no different to other people who live with a disability and no less deserving of living a good life.

Together, we spent time exploring who Cathy is, what she enjoys doing and what would give her life purpose. This was crucial so that our vision and plan for Cathy was developed around who she was, her gifts, abilities and talents and what she enjoyed doing rather than Cathy having to fit into what we developed for her.

We developed a strong vision statement that included Cathy living in her own home in the community, having family and friends around, paid and unpaid care and Cathy doing the things that she enjoys most. On reflection, it needed to be a vision that would stand the test of time and one that could not be watered down where Cathy got a lesser life. We developed two vision statements. One that we thought that Cathy would have for herself and the other was for family and friends to drive us forward.

The vision that we believed that Cathy would have for herself was drawn from family and friend's knowledge and understanding of Cathy needs and wishes and is stated as follows:

To be around my family feeling loved and included, being clean and tidy, wearing nice clothes, with my hair looking good, and having choices.

Living in my own home with people with similar interests who I like, having fun and sharing a similar lifestyle.

Receiving good health care, enabling me to discover, explore and live my life to the full!

The vision to drive us forward in getting a good life for Cathy stated the following:

Cathy is surrounded by a network of family and friends.

She is loved and included and living in her own home, doing and choosing the things she loves to do, with strong secure (paid and unpaid care) and support.

Feeling her life is meaningful and that she has her place in the fabric of life.

With the vision developed, (one that we would regularly revisit and strengthen if warranted) we set about developing goals for some of the practical aspects of Cathy's life. These included home, relationships and friends, communication, health care, financial matters, decision-making, and safeguards. There are other aspects of life that we could have planned but it would have been too daunting a task to set in place. Instead we chose the aspects of life that we could influence and would enable Cathy to have a better quality of life whilst she was living in the institution. We set goals for the chosen aspects of life and went on to develop strategies for each of these.

It was very important to me that we set goals that were SMART - Specific, Meaningful, Achievable, Realistic and Time-bound. It was too daunting to look at the overall picture of what needed to occur but these goals broke our plan down into bite size pieces.

The plan was not set in concrete but needed to be developmental and flexible enough to adapt with changing circumstances which inevitably occurred. Although, this might prove challenging for me it is what assisted me in the long-term. It was more appealing and less intimidating - that worked for me.

It was crucial to be intentional about developing a plan because without one Cathy would have either ended up living her life out at the institution or living somewhere else not in her best interests. From my work experience as an individual advocate I was aware that I needed to be proactive and not just rely on the service system to meet Cathy's needs and keep her safe. It has been critical for me to develop strong safeguards to keep Cathy safe and the best safeguards have been to have unpaid relationships in her life.

Furthermore, I clearly understood that I should not wait for funding before developing a vision and plan for Cathy's life. This would have been too late. I have also learnt that funding can also contribute to Cathy's vulnerability and that an individual package with Cathy's name attached to it does not guarantee that Cathy gets the life that I had envisaged and planned for her. There is more work to be done to create a great life for Cathy.

The planning that we did for Cathy was not about planning that many services may ask people with disability and their families to participate in. This planning was about creating a 'good life' that has meaning for Cathy and one which she finds fulfilling - a life of purpose. No one asked us to do this. We took control and decided to do it. The service planning is often just about getting through audits and the requirements of service agenda and not really about creating a fulfilling life for the person with disability.

Cathy has a placard on her wheelchair which was given to her for a recent birthday by a close friend. *"God has a plan for my life. It is so far behind schedule I will never die!"* This means that we need to continue reviewing what is happening for Cathy and be prepared to make the necessary changes to ensure that she has a great life now and into the future. For me personally, to achieve a great life for Cathy may take tears, time and enormous effort, be challenging, be fraught with hard and difficult discussions but I know as her twin sister she deserves the opportunity to have a good life doing the things that she enjoys most with people she chooses to have in her life - just as I have had.

Although, Cathy's life may well be richer than it was six months ago, we are not there yet - it is still in the making and will only happen by us being willing to challenge the status quo and be prepared to actively build a good life for Cathy.