

My Life, My Home, My Solution

Madonna Nicoll draws on her experiences of living in four different arrangements in her pursuit of a lifestyle that is authentic for her. Her experiences have given her insight into how different circumstances can either impede or facilitate a person's lifestyle, based on their needs, likes and desires. In this contribution, Madonna shares some of these insights about how she has created a life by influencing support arrangements according to her own expectations.

I was born with a physical disability and was raised by my paternal grandparents. They were the most amazing people and I loved them dearly. However, many times over the twenty-two years I lived with them, their dreams and my own differed greatly, significantly influencing some of my opportunities and happiness.

I lived with my grandparents and attended a special school during my primary years. When it became obvious that attending to my needs was becoming more difficult for my grandparents, I chose to become a weekday boarder at the residential facility where I had attended primary school. Around this time, I also decided to pursue regular education. I attended the local State High School, participating in regular classes with the option of seeking assistance through the Special Education Unit when required.

The residential facility was not a home. It was a building that provided shelter in a restrictive, inflexible and often frightening environment. Meal and bed times were fixed. I was wheeled through main hallways from bathroom to bedroom in a shower chair with little more than a shred of a towel to maintain modesty. This was degrading, being in this situation when visitors were escorted into the private sections while this was happening. My friend and I dreamed of a day when life wasn't focussed on physical assistance, homework as designated by others. Our basic needs were met but the support was at times less than desirable – the fear of retaliation maintained our silence about bad practice. I always complied with workers whom I feared the most – not saying anything even if they hurt me.

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Some in-home support became available after three years living in the institution, so I returned home to live with my grandparents while finishing my schooling. It was a huge relief to move 'home' and know that I was loved. However, my grandparents had more control over my life than I did. As a young adult, I wasn't permitted to have my own key and return home late at night like a lot of my friends. I didn't get to go nightclubbing or do many other youthful pursuits at age 18 because my grandparents were frightened of what could happen to me.

This is when I started to develop the idea of my dream life. I dreamt of a day when I would live in a home of my own choosing, fill that home with my own personal touches, do what I wanted to do when I wanted to, live with people I chose, have parties and take part in life! A part of this was the opportunity to make my own decisions, make mistakes and learn from them and be successful. My best friend and I made an application for public housing. We had shared the educational journey and institutional life and at this time, the choice to live with another person with a disability was our decision, not anyone else's. We were first and foremost best friends. The fact that we shared the commonality of disability did not mean that we should or should not live together. It was our choice.

Of course there were a number of issues that impinged on the realisation of my dream to begin with. My grandmother was highly concerned about my safety when my friend and I finally moved into emergency accommodation. Much to my discontent, she used to tell me all of the things that could go wrong. However, as I pointed out, these were the same for anyone moving out of the family home and I had a right to make a home of my own so that they too could live their lives.

When I had been living on my own for a number of years my grandmother admitted to me that her concerns were unwarranted. She had watched me learn and grow from making my own mistakes and experiencing life. My friend and I learnt quickly about the freedom of having our own home. 'Stanley' was often a companion of ours and when asked who 'Stanley' was we would look at each other and laugh and tell that person to look in the fridge. They quickly found out 'Stanley' was a cask of wine, which we enjoyed together with many laughs. I believe if my grandmother had been there at times I would have received a stern, "Madonna, you really shouldn't be drinking that." We had a ball but mostly we just lived.

Another impediment was sharing support arrangements with my friend. Sharing the amount of support and all of the arrangements about staff compromised one person's lifestyle such that the other person could not do what they wanted or needed to do. As time progressed we realised that although we loved each other we wanted our own space. However, we were still restricted by the number of support hours.

After many years of applications we both received individualised funding. With the separation of our support arrangements, we now moved into our own homes while maintaining a strong, unfailing and long-term friendship.

I am now living the dream in my own unit with my cat and cockatiel. I make all of my own decisions, including the nature of support. Physical support is extremely personal, requiring a trusting relationship, so I interview the applicants. Having control of my own lifestyle requires organising my own support rosters to have a flexible, free lifestyle that makes me happy. Most often this support relationship develops into friendship that exceeds the working relationship long after it has ended.

These experiences have made me a well-rounded, competent person. More importantly, over the years I have had experiences. I have laughed, cried, and been happy, sad and angry. I have worked, studied, partied, made friends, lost friends, started a relationship and ended a relationship. I have watched both of my grandparents and my best friend pass away and have grieved for them. I now continue the journey with my father and many great friends and continue to look forward to the next great adventure – you just never know what waits around the corner.

My original dream was about bricks and mortar but it became so much more.