Leading my Life through my Vision

Narissa Wilson *was born in Mount Isa and lived there with her older sister and parents. She was diagnosed with Spinal Muscular Atrophy at 18 months of age. Narissa has been living independently and calling the Sunshine Coast home since 2004. She now lives in her own home with her partner and house mates of her choice. She manages her own funding which she ensures is aligned with her vision of the life she wants and needs.*

Life is not a painting on the wall, nor is it to be lived lonely. It is a substance you inhale and live happily. We strive for the best, unfold our wings and believe. Life is fundamentally unstable, though we all carry a false sense of stability, control and power. Our relationships, endeavours and our lives are all simply systems. Systems can absorb damage, change and growth, to a point, then, all of a sudden, everything switches to a whole new set of rules. My family learnt this twenty six years ago when the stable state of their healthy new born baby girl switched to a whole new set of rules.

When I was little, hiding in my cubby house, made of duck printed flannelette sheets, with my heart open, I had a vision for my future, just like the one I was creating for Barbie and Ken. Barbie had the best life! She had beautiful long blonde hair, silky plastic legs, great clothes, and a beautiful yellow Sesame Street house, with a blue roof. She was intelligent, had a white double bed, a handsome husband, Ken, and she was in control of her life. Barbie and Ken lived their life happily under the duck printed flannelette sheets until one day, Barbie's hair got cut off by my big sister. Ken's arm broke off and got sucked up by the vacuum cleaner. The yellow Sesame Street house got stored in Dad's shed and the white double bed Uncle Snow built was given away to another little girl along with Barbie's clothes. Thankfully, I got to keep her intelligence and the vision that life could be great. My legs are not silky and plastic, and I settled for black metal and round motorised wheels to make my way through life.

Within the world I created, Barbie had control and power over her life; this was what I wanted for my life and what I now feel I have. Having control and the power over the direction of my life allows me to live. For me, Self-Managed Support means that I, the individual, direct the way my life lies, faces and moves in reference to my visions. Working with and along side a service is much more satisfying than against. I was previously supported by a traditional service provider who endeavoured to be individualised but was unfortunately limited in its ability to colour outside the lines. Traditional services are not necessarily big bad wolves; they are simply bound by regimented ways of thinking that expect they can control those sudden changes in a stable state.

Self Managed Support works for me through a hosting agreement with a service. To me it is a business and I am the CEO of my life. The business is like any other and requires annual planning, weekly analysis of operations and staff, budget reviews, team meetings, team professional development (for myself and staff), policies and procedures and much more. My business operations consist of my service receiving and reporting funding to the Department of Communities. I have a direct relationship with my service, whom I have a Self Directed Hosting Agreement with. I am the person receiving and directing support (the business). I share the Governance with key people of my choice such as my partner, family and people I have identified to assist in the direction. To assist me in the management and HR, I have a paid Key Worker who communicates with the Staff, Governance group and myself under my direction. My support team (HR) consists of 5 Support Workers. To occasionally supplement my support team, I maintain a casual support team (contractors) who are people in my life that I have built relationships with. They are able to support me with minimal support in the need of an emergency or over the holidays.

Self Managed Support has allowed me the flexibility and freedom to live a life style that is bound by my choices, in my home and community. I now have the ability to build the relationships with the people I choose to be a part of my life. For me, what I appreciate the most about Self Managed Support is that I can now create a workplace culture with my employees that enhances our productivity, knowledge, willingness and overall happiness. I can align my philosophies of good business practices with, most importantly, a positive culture for people with disabilities.

To be in control, doesn't come easy! It took an investment in myself as a leader for Self Managed Support. It was time consuming in the beginning to gain the knowledge and set up processes that would work for my life. I need to be willing to make mistakes and learn from them. Communication is a skill that opened doors for me to improve my business, the relationships I had with my staff and my life. Like any challenge it can be overwhelming and for Self Managed Support it is 100 times more because it is personal. Thus, I have had to learn (which I am still not good at) to separate myself from the "issue/incident" and analyse it critically. One of my biggest learning curves is that I cannot do it on my own. I require assistance with Governance, from a group of people who can offer me support. Every business has an advisor.

Barbie and Ken did not get to where they are by just sitting on a store shelf. It is about leadership in their market. This is no different for Self Managed Support. I am the leader for my life and my business. A leader needs to know who they are, what they want and how they are going to get it. To understand how and why I make decisions is what has helped with being a leader. My partner, family, governance group, key worker and support workers are all leaders too. They share my vision, my dreams, the good times and the bad times.

Barbie's hair never grew back and Ken's arm couldn't be re attached. However, I crawled out from the duck printed flannelette sheets, and I worked hard to move out of home with formal and informal support. I also worked hard to receive a degree in Information Technology (e-commerce & design), to be a general manager and project manager, and to run my own web and graphic design business. This was all possible because of my vision and those who shared it with me. I want to continue to be a successful business woman, to travel and to be the best sister. I want to be a daughter who my parents can be proud of and a girlfriend who loves and supports her man. I want to continually grow, expand my knowledge and to simply just live to love life. I can dream and plan for all these things because I know that I have the power and control I need over my own life.