Mike's Story

Mike wrote his own story.

For many people with disabilities, there are barriers to them finding who they really are.

Personhood is often denied to people with disabilities because other people have control over us. If we rely on other people, we learn to become subservient. Or some people become quite loud. Yet personhood is tied up in our humanity. And that humanity, for me, involves a spiritual dimension. This is the story of my search for my personhood.

The heart of my life is in the West End of Brisbane. I can walk to the shops, I can walk to church, I can walk to an accessible railway station—I live in an area which endeavours to be more of a community than just a suburb.

These were all part of the criteria I set with my group of friends before setting out to find my own place. Currently I am the inaugural contact person for Luke14 Brisbane, a group dedicated to the inclusion of people with disability in church life.

I have also, over the last 20 plus years, been president and an ongoing executive member of a systems advocacy organisation, and president of the only grassroots change and capacity building agency in the disability sector in Australia, a Queensland disability housing peak, as well as a cutting-edge supported accommodation organisation.

I type by using a ‘pointer’ attached to a steel band around my head. Some people seem to get put off by my speech, especially initially. I try to let people know that I don't want them to be put off because I really don’t mind how many times I need to repeat myself. I use a motorised wheelchair.

I would say I’m a spiritual person – without this, my having a disability wouldn’t make any sense for me. I perform the role of Eucharist Minister which is very much a highlight of my week! As a kid I felt I had vocation within the Church, but because of a number of factors this never eventuated. I love buying books; especially theology, philosophy, and psychology books. I’m a people’s person, a people watcher. I love a joke, and love music, especially jazz.

I firmly believe that positive change for people with disabilities is absolutely necessary, and is possible!

The factors that have enabled me to move forward in my life despite many hurdles relate to the person I am. Somehow, especially as a kid and despite these hurdles, I always felt comfortable in myself.

If something went wrong—which often happened—I always felt it would be righted. I have always had a fascination with people, and a belief in their innate goodness—although I have been wronged many a time. I suppose I believe that we humans are basically good despite our fallen nature.

It's so important to always be in touch with oneself; one must be in touch with oneself, before one can be in touch with each other. Our basic instinct is that of a social being; but we can't be social until we know—and are comfortable with—our unique selves.

Many people with disabilities grow up thinking they have to be grateful and need to please. Thus, ultimately their real identities are subsumed and eventually utterly eradicated.

Life, for me, has had many ups and downs, but thus far I have always managed to come out the other side with a bit of a smirk on my face. These ups and downs have taught me many things about life in general, as well as about the human condition.

Mum told me that when I was a young baby, I cried a fair bit—nobody knew why. Apparently my birth was quite traumatic, and I think one doctor said that things didn't look hopeful—what that meant in those days I really don't know.

As I grew older, I wasn't doing the things I should have been at that age. When Mum finally took me to a doctor, he just said that I was simply a slow developer, and that I would 'come right' in time. I didn't 'come right'!

Somehow, someone figured out that I fitted the cerebral palsy label—I never quite found out how all that happened. I know that I was one of the first to attend what was called in those days the Queensland Spastic Welfare League. I started there, aged 3 or 4, being one of the first to attend their kindergarten.

I enjoyed school. I enjoyed learning about things. I also think that I saw school as a social occasion. Teachers and therapists would fight for 'ownership' of me. I had the three therapies (physio, occupational and speech) daily as well as standing in standing frames.

I went through school, reaching leaving standard. I never sat for any examinations—likely because nobody had any expectation that I should or would want to. Though I had completed my secondary school studies, I was not qualified to do further study. So, what to do now?

Through some fated stroke of luck or misfortune (depends how and when I think about this), I fell over the line to gain entrance to the Sheltered Workshop. After doing a number of typing jobs—tedious and quite boring—I finally graduated to doing the invoicing and basic accounting-type jobs for the workshop.

Little did I know then that later on, I would hold down the role of treasurer of a supported accommodation agency for quite a few years. It was around this time—the 1980s—that I really started to wake up. I figured that if I didn't get out of that place fairly quickly, I could well end up rotting there. I also figured that probably my only avenue out was education.

After a few unsuccessful attempts I was finally accepted into a Diploma of Community Welfare course. From there I went on to do a Bachelor of Social Science and completed a Counselling Course at the Institute of Pastoral Care, Archdiocese of Brisbane, in 1982.

I survived a twelve year period in an institution, relatively unscarred emotionally. Although I had difficulties adjusting to the institution, for me the institution was a place of good necessary learning.

I learnt a lot about the human spirit. I learnt a lot about what makes people get out of bed in the mornings. I learnt about power, oppression and vulnerability. I learnt a lot about injustices, social injustices.

I learnt about my own personal views, vision and virtues, particularly those pertaining to the general concepts of personal and collective empowerment, participation, self-determination, access to resources and opportunities, and I developed a strong belief in building communities that are totally inclusive and accepting of ‘other’. For such insightful and precise learning, I hope that I will be eternally grateful.

Whilst in the institution, I helped to establish its first Residents’ Committee. As it has turned out, being the inaugural president of this committee was the precursor to becoming the inaugural president of a state-wide advocacy organisation and a supported accommodation service—isn’t it great how the wheel keeps turning?

I also managed to escape the institution in a rather bloodless coup.

The virtues of the Commonwealth Disability Services Act of 1986 were many. One of the many merits of this landmark piece of change legislation was the credence it placed on Demonstration Projects. I became one of four in such a project with the label of having high support needs. To this day, I am still bemused as to what this term really means—anyway, I must have fitted the box.

This Demonstration Project worked out very well. It was based on an empowerment model, which eventually was included in the broader term of supported accommodation.

In our demonstration we were taught about how to hire and fire workers, to train and manage workers. For me, this was a great time. There were lots of people around—including researchers from the university, group facilitators and so on—apart from the four of us compliant guinea pigs!

My first job in open employment was as an Advocacy Support Worker, which ceased after two years because of a complete funding cut to that particular project. I thought at this time (the early 1990s), jobs were going to be difficult to come by, so I thought I had better go back to university and get another piece of paper (perhaps I really just wanted to go back to school again?).

I did a three-year degree course in two, because I was able to obtain credit from my previous diploma course. It somehow wasn’t quite as good the second time around. And I suppose I was doing it for reasons outside of myself—I am not too sure.

As I said, the Demonstration Project was such a success—it eventually became a service. I lived there for about five or six years, but somehow I just didn’t feel at home with congregated living—for me it often reminded me of the institution. So my aim in life was to get a place of my own.

I was very fortunate indeed to be able to gather some very wonderful and beautiful people around me. They were people with whom I felt completely at ease to share my deepest longings. I knew I could trust them completely. I knew they would follow me anywhere I wanted to go. Together we took on the Department of Housing and won. Together we took on the Brisbane City Council and won. Together we strategised everything—but I think most of all, we enjoyed whilst in the battle.

When I decided that congregated living wasn't for me, I began to dream. Why couldn't a group of us simply set up our own service? So, we did!

One of my fondest memories is when other radical visionary mates and I wrote the funding submission. With the help of a few Baileys and milk, one fairly cool weekend we poured our dreams onto paper; we even developed a fairly spot-on budget. Eventually our submission was looked at favourably by the Federal Government and our own service was born.

Lifestyle Options Inc. (LOI) is a consumer run organisation, currently providing personal support service for fifteen or so people with disabilities who, prior to receiving funding, were in danger of being admitted to a nursing home or institution due to lack of appropriate community based services in personal support.

There are six people on the management committee, all of whom use the service. In addition, all members are invited to regular consumer forums to discuss and determine the organisation's policies and talk about other issues that impact on the lives of the members and other people with disabilities.

The service provided by Lifestyle Options endeavours to give consumers optimum control in the provision of their own personal care. The policy for dominant consumer representation on the management committee is aimed at empowering people with disabilities by example of an efficient and well operated organisation.

The skills possessed by the Lifestyle Options management committee members were learned. Similarly these same skills can be learned by other people with disabilities, given the confidence and opportunity to do so.

Lifestyle Options is highly individualised and also collective in nature. Each of us wanted autonomy in our own lives, but also recognised the value of working together and having the back up of each other and a service that we had a lot of influence over.

While it is true that there are a number of other self-managed models for people with physical disabilities across Australia, Lifestyle Options has evolved a model that includes some people with multiple disabilities.

It has also retained its collective nature and this has been a great safeguard on the original vision. The experience of members of Lifestyle Options have left them with little faith in the capacity of larger providers managed by remote boards to consistently pay attention to the interests of each and every person over time. Lifestyle Options represents the best option that is available for all of us.

I have had some very fine people around me through my life. However, it must be understood that it is only in giving does one really learn to receive. Thus, if folk (e.g.

people with disabilities) are only given a chance to receive, but never or seldomly have a chance to freely give, there is no basis for learning to receive.

This is very much a process of reciprocity. Some folk may seem to ‘need’ more than others; reciprocity does not have to be equal give and take. When people without the label of disability give, it should be done with humility, thankfulness, in a non-patronising way, and in recognition of the other’s personhood.

Following are suggestions and observations I would like to make to other people with disabilities, who may be facing similar issues:

1. Find your true selves. We are not broken; we cannot be fixed; we are not clients, nor patients. We are not sick. Each of us is a unique human being and each of us has to find what that means for each of him or herself.

2. Accept your true selves. There are things about each of us that cannot be changed and so we need to accept our uniqueness.

3. Embrace your true selves. This is about embracing the process of finding and accepting our true selves through being open and honest about our beliefs about what life is or could be about. It is also through finding hope and finding those things that give us hope.

4. Love others because of our shared humanity and because we are all searching for personhood.

Peace!

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