

Nadia's Story: Toward a grander vision of disability and society

Nadia wrote her story.

Acquiring Disability

I was born in Adelaide in 1962 to two immigrants from Italy. In the mid-70s, at the age of 12, I had a subarachnoid brain haemorrhage. The cause of the haemorrhage - an arterial-venous malformation (aneurysm) - meant I had a bleak prognosis. I experienced the pros and cons of the public health system and am only here today to tell the story because of my devoted parents and the amazing medical staff at the Adelaide Children's Hospital.

One of my parents was by my bedside almost 24 hours a day steering me through critical time periods when the nursing staff failed to act. My prognosis was a 99 per cent chance of a second brain haemorrhage, and with no defined timeframe, the risks of surgery at that point were too high to contemplate.

Institutional Life

The doctors told me I would never walk or move my arm again and not to bother trying to go back to school, just to enjoy my life. I was transferred to an institution but my parents fought hard to have me discharged home. They were told they wouldn't be able to cope with me and my mum was even sent to see a psychiatrist for wanting me home! The care I was getting in the institution was un-inspirational, it was obvious to me that the staff did not want me there but even more so, did not want my mum milling around.

My parents fought the system until they were allowed to take me home, undertaking responsibility for my rehabilitation. My parents hired a heated pool near our home for an hour every morning before the squads started swimming (because I was too embarrassed to go when they were there). I learnt to walk again in the pool. I returned to school to complete my education and recommenced in year nine. Unlike most teenagers I was unable to work part-time or do work experience as part of my curriculum.

A Second Aneurysm and More Surgery

Four years later, when I was in year 12, I had another haemorrhage. This one was bigger and meant that if the aneurysm wasn't removed I would have a third haemorrhage and die. There was now no other option but major brain surgery to remove the aneurysm. The chance of surviving the operation was 20 per cent.

The Challenge to Maintain School

Following a nine and a half hour micro surgery, I was put on large doses of anti-convulsive drugs to reduce the chance of blackouts. I negotiated for the dosage to be reduced over the ensuing months because I wanted to go back to school and live a "normal" life. I didn't listen to the doctors again. The doctors threatened me with

epilepsy and said I couldn't manage school, shouldn't worry about it, and should just enjoy my life.

Education

I went back to school the following year to complete year 12 and graduated in 1980. My final score was 374/500. I was accepted into the University of Adelaide to study a Bachelor of Economics. In the meantime, my parents funded my ongoing rehabilitation. The only way I could manage and maintain my mobility was through ongoing rehabilitation – mostly hydrotherapy, gym, work and exercise.

At this stage I was 18 years old and looking for a job - I had never worked before. I was very depressed because nobody would even interview me. I eventually got a four week opportunity at a private company. My mum, by this time, had started working and went to her human resource manager and asked if there was anything I could do there. He told her not in their workplace but gave her the number of a disability employment network. I contacted this place and was asked to come in for induction. As a result, I got an interview for a temporary position in the South Australian State Government. I started work and eventually won a permanent position. Several years later, in 1987, I received a promotion.

I changed my studies to part-time but found that full-time work, ongoing rehabilitation and part-time study was too much. After completing five and half subjects of a 10 subject degree I withdrew because I was told that the degree had to be finalised within 10 years of commencement (a pressure I did not need).

I got married and had a child. After a period of accouchement leave, I kept working full-time (it is very expensive to live with a disability and remain independent).

Restricted Opportunities

During this time I felt I was not getting the opportunities for advancement at work. This was not an easy time, but I tried to stay focused on what I thought could be possible in my life. Also, because I was working in the department I realised a few things about the disability sector generally. I found it was not easy for people living with disability to get information about supports. I also felt that government were missing out on having more people living with disability in their workforce; there are many good people out there. So I began to advocate that the government do more to get people into work.

My own personal breakthrough came when I was moved to a new position and a new manager...".

Learning from other examples

I noticed the units advocating for the indigenous population achieved great results by advocating for realistic targets and ensuring adequate resources were invested in achieving these targets. I congratulate them. I would like to see this happen for people with a disability. Similarly, I acknowledge the work that has been done to increase the number of women in senior roles and board positions. This initiative has been supported with the establishment of quotas and investment.

A New Manager, a New Qualification and a New Position

When I was moved, I was fortunate to come across a new manager. This lady was empathetic, supportive and client focused. With her support, I commenced a Diploma in Project Management and completed it successfully in 2011 - achieving all distinctions. I then successfully applied for a temporary position in the Department of Health and Ageing in a newly established unit. I started in this position the week I started in the Leaders for Tomorrow program. This position particularly appealed to me as it is located in ClinEdSA, a Commonwealth Government funded initiative where I hope I will be able to influence the education of Allied Health students for the better.

Identifying Enablers

As part of my development in the Leaders for Tomorrow program I studied a Company Director Course with the Australian Institute of Company Directors and I am now post nominal. I am a graduate of the Australian Institute of Company Directors. So what has changed for my outcomes to start improving?

1. I found out about job access and their services
2. I found two managers who had an open mind about employing people with a disability and supported my development.

I think there should be more advertising about job access so people don't fall through the cracks like I did. I also think it would be a good idea to educate managers and prospective employers about the benefits of employing people with disability.

I am trying to place myself in a position where I can influence and make decisions that will improve outcomes for people with a disability, particularly employment opportunities.

A Way Forward

In conclusion, I propose a vision for the way forward:

1. Focus on social inclusion through better/more employment opportunities
2. Employ people with a disability in decision-making roles wherever possible - I am hoping that is going to be a mandate for the NDIS offices to employ people with a disability wherever possible including leadership positions.
3. Create targets for people with disability to be on boards, and employed as a percentage of the workforce, as opposed to quotas.

4. Focus on changing the culture of disability service organisations and providers, including government, so that they are a customer service unit that listens to clients and actions complaints. Complaints should be viewed as an opportunity to improve systems; this will change the whole focus. I think this would be best achieved by establishing a customer service unit in each of the new NDIS offices, offices that focus on customer service, Safety and Quality and setting the culture of the organisation
5. Ongoing support and training for clients and Managers.

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