

## Michael's Story

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*Michael wrote his own story.*

I was born in Adelaide South Australia in 1952 and was adopted soon after birth. I was born with low vision, undiagnosed until I was five. Until I was 29 years old I used no mobility aids. I blinked a lot more than most people, because my eyes were super sensitive to glare and were trying to shut out the light. This was the only constant indication of having an impairment and only in conditions of bright light.

I was only able to recognise a friend's face if they were 3 or less metres away: beyond that things got blurry. I could read telephone books and street directories but I had to get the print about 2 or 3 centimetres from my eyes. This made me a really slow reader. During daylight I couldn't cross busy roads without traffic lights and had to follow the other pedestrians as I couldn't see the "Walk" signal: there were no audio – tactile lights until I was in my 30s.

At night I could get around much more easily and when I was 17 I learned that I could safely cross busy roads at night. By the time I was 21 I rode a bike just about anywhere around the metropolitan area so long as it was at night.

### **Growing up apart from having low vision**

I was and remain a deeply committed Christian. Most of my growing up was through Churches of Christ and from my late teens through the ASCM (Australian Student Christian Movement) before joining the Catholic Church in 1981. Although a very slow learner the challenge and compassion of my friends in the ASCM and my wife Cathy taught me over a 15 year period the importance of unlearning some of the things that I had believed to be crucial to my identity.

Over time I started to shift my view what I wanted to be. I began learning to value:

- listening rather than persuading
- becoming aware of how other people were feeling rather than focussing mainly on me
- building a resilient marriage and nurturing children rather than achieving professional success in the world of paid work.

People who take these attributes for granted may be puzzled about my long journey but I was a long way from these behaviours in my late teens. For me the **high** news of Jesus was in part accepting that I was loved whatever my flaws. This freed me to learn about who I could become and how this could happen.

I had to apply this learning when I realised that my effort to be a published political economist was going to cost Cathy a great deal as we both saw ourselves needing lots of time together if our relationship was to endure. So I stopped striving to be published for a while and we spent more time together. We were married in December 1980 in the chapel at the University of Adelaide followed by frog cakes and lamingtons in the cloisters.

## **A vision impairment is just part of living**

All that was taking place while my vision impairment was becoming more severe. Until I was 30 years old I strongly avoided identifying myself as being blind or living with disability. From when I was 16 I could have been more mobile during daylight by learning to use a white cane which was offered to me by a neighbour who was blind, but I didn't want to be seen as a blind person.

I thought that would make the mating game even harder for me. I was already behind other boys who were starting to learn to drive and I knew that I never would. It is only when you can't do something that most people can that you realise how some everyday things are really much more significant than we appreciate. Driving a car is both a rite of passage to adulthood and very useful for developing relationships, or so it seemed!

In my early years I had struggled at primary school. When I was 7 I resisted going to a special school preferring to stay with my friends. But the teachers as well as I didn't know what I was missing due to my short sightedness. For example I had trouble with putting words in alphabetical order in junior – middle primary school.

It wasn't until year 5 that I discovered that the alphabet was written in large letters on top of the blackboard at the front of the class room. Everyone else in year 4 and 5 would refer to the letters on the front wall they were facing when doing alphabet exercises and I was unaware of this.

With experience and help from my parents and teachers I gradually learned how to make the best use of my vision. (I later resisted going to an independent school when I finished primary education because I wanted to be at the same public school most of my friends would go to). When I was at university I chose subjects which didn't require reading information on a black (or white) board and negotiated for extra time in exams since I was slower reading and writing than others.

My reluctance to advertise that I had low vision meant that people who didn't know me well saw me as snobbish because I wouldn't return their smiles or waves when we passed and were more than 3 metres apart: I just couldn't see waves and smiles beyond that distance.

Just before I met Cathy (when I was 25) I had begun to lose this level of sight. I didn't realise this for 3 years because the change was slow. By the time I started a Master of Arts degree in 1981 I had to use print magnification technology and within a year I had to make a decision about whether to learn to use a white cane to get around. The alternative was not to get around independently.

This was a time of growing up. I feared that people who had known me for years would start to see me as less capable in many areas of life just because I would be using a white cane. I struggled with this fear for six weeks in 1982 and it was Cathy's wisdom and support which gave me the courage to step into a new life as a person who would be seen to have a disability by others simply because I used a white cane.

Experience from my time in the Student Christian Movement also helped. I recalled a good friend in the ASCM explaining to a group of us at a national conference in late 1974 how semi-conductor development was going to revolutionise computing by

making it miniature and much faster. Tony Brown was completing a computer science degree at Monash Uni using Braille and a guide dog to get around.

With Tony's story in mind and greatly supported by Cathy's and my Orientation and Mobility instructor's positive expectations of me my confidence grew quickly. I was acquiring a really neat skill using the white cane and ultra-sound sensor. For the first time in my life I felt that I had mastered a valuable physical skill. I think this is what other people may experience in learning to play a sport.

Once again Cathy and I chose to put time into our relationship and soon to be family as our first child was due in June 1983. I withdrew from my Masters degree in late 1982 since the only way I could complete it would be through Cathy doing a lot of admin support and reading for me.

I began to apply what I had learned in the Student Christian Movement and from Cathy. I chose to combine adjusting to vision loss with parenting our soon to be family instead of trying to continue my academic career. This was one of the best decisions of my life.

Cathy started a part time Graduate Diploma in Reading Education and I tried to work out what income earning future I might have. I found the Commonwealth Rehabilitation Service had no idea about how to advise a political economy student who was now almost totally blind.

So in desperation I decided to do a Graduate Diploma in Further Education, trying to do one full time term before our child was born then taking a year's break to improve my Braille and mobility skills before returning to this one year full time equivalent diploma. I chose not to do a 3 or 4 year degree, say in Social Work, because it would remove me from active parenting and from Cathy for too many years.

Here this story breaks into two parts: my marriage and life as a parent and my training and employment in the paid workforce.

### **Marriage, parenting and being blind and poor**

Before our son was born in 1983 a social worker in a community services agency heard me talking about looking forward to our child's birth. She upbraided me for being so selfish as any child in my family would be condemned to growing up in poverty.

While I felt angry about this criticism, especially from a human services professional, I have to acknowledge that our children did grow up in poverty especially for their first few years. The criticism was also made at a time when there was no clear option for getting someone with my skills and background into the mainstream workforce.

I now believe that the criticism, made on behalf of children not then born, ignored some of the positive side of growing up with a parent living with disability. ("Disability" arises from both the vision impairment and the web of exclusion which restricts full economic participation even today.)

The 1980s were really difficult for us as we had to survive on a Disability Support Pension and both of us began learning about parenting. Like many men I was

scared of being left alone with our child Joel as I didn't know what to do other than change nappies, talk with him or listen in when Cathy read to him.

In 1984 Cathy's parents would travel by bus from Belair, an Adelaide hills suburb, to be with Joel and me when Cathy had to go to lectures. But one day when Joel was about 15 months old Cathy had to attend a class when we couldn't find anyone to help me with Joel. We had just moved into public housing in the previous fortnight and didn't yet know our neighbours.

So I was to be the only adult at home that day. My idea was to keep Joel busy and I had all kinds of half thought out activities. But something made me calm and listen to what Joel wanted to do and the time sped by as he showed me how he wanted me to play/work with him. It was a revelation about very young children who are entirely capable of getting on with their lives and showing their parents how to join in.

For both Cathy and me, parenting Joel and then Lucilla (born in 1986) was a revelation full of delight and challenges. We discovered how very young children's potential is largely untapped in our society. I use the example of Joel's passion as a toddler and young child for getting out and about.

Now Cathy had given up her driver's licence before Joel was born so not having a car was our normal reality. We caught buses (no ramp entry in those days) with one and later two children, a pusher and a backpack.

One morning at Kindergym Joel who was almost two and a half wanted to cross to the other side of the unstructured play area through play equipment, gym mats and toddlers. He took my hand and by holding his right arm as high as he could he guided me among the obstacles with stunning facility.

From the age of four he showed an ability to read street directories before he could spell. He had asked for a street directory for his 4<sup>th</sup> birthday. When we travelled on foot, bus or train he took it with him. A couple of months after his 4<sup>th</sup> birthday I heard him turning the directory pages occasionally as we travelled on a bus through Adelaide's beachside suburbs from Grange to Henley Beach.

This bus service then turned east onto Henley Beach Rd to head for the Adelaide CBD. I asked him if he could show Cathy where we were. It happened that we were at the intersection of Henley Beach and Military roads and he pointed at this intersection on the map. We still don't quite believe it!

Given that I wasn't much fun to play ball with Joel at about 3 years old, invented a game where he would ride his trike pretending to be a bus or train driver, giving me various roles as passengers or other people he interacted with. He developed stories using real timetables and local items on TV and radio news as a structure for these.

Early in his time at Kindergarten he had me saying the names of the streets listed in timetables: he spelled out the street name, I told him the pronunciation and he never forgot after that. One Sunday lunchtime soon after his 5<sup>th</sup> birthday he suggested that we catch a bus and a train to a south western beachside suburb. We both said "yes" and began our journey of being amazed at Joel's grasp of time and space.

He already had the bus and train timetables and with his trusty UBD street directory took us without incident to Seacliff railway station, for a half hour's walk around the area and home again in plenty of time for dinner. From there began hundreds of evening and weekend trips for Joel and me. He decided where he wanted to go and I accompanied him over the next 14 years until (actually even beyond that) he had his probationary driver's licence.

Soon after that Seacliff trip he took me to the busy beachside suburb of Glenelg on a winter's Saturday night. He wanted to cross the very busy Jetty Road (in the dark) and asked if that was OK. Flashing through my mind were thoughts like:

"This was bound to happen some time but so soon?"

"Joel had full adult sight just after his 4<sup>th</sup> birthday according to the Dept of Education health and development check"

"What will Cathy think if I agree to cross with him".

He was so quiet and patient that I had to say "yes". He waited for a break on one side of the road, got to the middle and after a short pause completed the crossing so matter-of-factly that my confidence in his ability grew quickly. He never made a dodgy road crossing with me at any time.

Not to leave Lucilla out of this picture I also travelled across town with her weekly to 2 – 4 Music Group. It was in a suburb where I had grown up so I had a general idea of the street layout and could tell her to turn right or left. We arrived at the music group calmly and safely and home again the same way for several months.

Every parent thinks their child is special and they are right. But I think Joel's and Lucilla's experience shows how much untapped potential very young children have.

There is rightly much focus on the unemployment of people with disabilities. But there is almost no research into the experiences of families with a parent with disability and what this can mean for partners and children. So often the community and government sector assume that my wife will make up for the inaccessible documents they expect me to read by proxy.

My impairment has along with Cathy's pioneering parenting led to two young people who neither ignore nor romanticise impairment and disability. As Lucilla said when interviewed as a 17 year old volunteer with a skills program for young children with disability: "Disability is no big deal. It has just been part of growing up in a family with a blind dad".

But after 8 years on a disability Support Pension, even in concession rent state housing, our resources were running out. The washing machine broke down and generous friends gave us the money to replace it. Then the fridge died and I went on the charity run asking for assistance to get this replaced and to supplement our food as we had to use everyday money to pay for a cheap second-hand fridge.

Cathy had started some temporary relief teaching and while she enjoyed it she was adamant that the paid workforce was a poor alternative to spending time with Lucilla (now 3) and Joel (now 6). This was her mission in life during their childhood.

So I now switch to my training and employment story.

## **Getting a job blind where I couldn't get one when I had useful low vision**

My experience when I had useful low vision, after graduating in Honours Politics in 1976, was an endless series of public service tests for graduate positions – they always said I came near top of the class although I can't verify that. I submitted private and community sector applications all with one thing in common: no job resulted.

In the mid-1980s a courageous and visionary man, Mike Fulgrabe, left his work at Flinders University to become the manager of the employment preparation program at the Royal Society for the Blind at Gilles Plains a mid-north-eastern suburb. He set up the first "PC screen reader" and word processing training course in SA for people who are blind and looking for work. It was a sign of the times that all of the trainees were male.

The adaptive technology was very basic and there was limited support if you managed to get a job or training placement and had computer problems. I had a short time in a training program but couldn't get on top of the PC problems that developed during this placement and quit after 11 months. After that I returned to full-time parenting and some sessional teaching about disability awareness in TAFE and the childcare sector.

But better technology was on the way. A neighbour in the next street made her Wednesday and Saturday newspaper employment section available for us and twice a week Lucilla, Joel and I would go around to Rae English's house (she was a local Councillor as well) and pick up the employment advertisements, Joel and Lucilla taking turns to do this.

Joel and Cathy would read through the ads and I started applying for jobs, getting short-listed in November 1989 which boosted my confidence. By May 1990 at age 38 I won my first job, working for a Commonwealth funded disability advocacy agency in a joint venture with the trade union peak body in SA.

Getting to and from work was a challenge as there were some hard high volume traffic intersections to be crossed. But Guide Dogs Association orientation training and my white cane proved up to this challenge.

Other than the admin staff I was one of the few staff to have a PC plus a document scanner. This job gave me the chance to present submissions to Commonwealth Parliamentary inquiries, to participate in disability employment forums of the Australian Council of Trade Unions and to work with a number of SA unions interested in promoting employment of people living with disability.

It is hard to be sure in hindsight, but I think that if I wasn't entitled to a Disability Support Pension (Blind Persons) it would have been a much harder struggle to stay employed without Cathy having to work at least part-time. The DSP for blind people at that time wasn't means tested. This gave us the chance to pay back some debts, re-build our worn out appliances and household necessities.

It meant we had money for the occasional taxi to get me home much earlier on Fridays when Joel and I would then go out on the buses shopping at the Central Market, in Rundle Mall and suburban video hire stores getting home at 9.30pm.

From early 1994 Joel began to travel independently on buses and trains and would meet me after work most days so we came home together.

When the Howard government was elected in 1996 the funding was terminated and at age 44 I was job hunting again. My wonderful manager, Mr Steve Key, broke the news to me on the day Joel was having his 13<sup>th</sup> birthday party at the Belair Hotel in the Adelaide Hills where Cathy's parents lived. I didn't have the heart to tell them about being given notice until the next day.

My employer gave me a generous redundancy package by continuing to fund my place in a generic management consultant training program I had begun in March. The Christopher Hamilton and Associates team must have seen me as a challenge that they took up with enthusiasm.

I was told that managers in their mid-40s were taking about 6 months to find any kind of new employment and that it might be a bit longer for me. After lots of cold canvassing and networking I was appointed to a 12 hour per week role as the lay Catholic Chaplain at Flinders University in April 1997. It required two buses and 75 minutes each way two days per week so Cathy, Lucilla and Joel started to see less of me.

The Adelaide Archdiocese soon upgraded my pay from a priest's stipend (then \$21,000 pa) to an equivalent community sector salary and increased my hours to 15 per week. I truly loved the work and began building a cross-faith management committee for the Religious Centre as well as working with the other Christian Chaplains to make sense of this role now tertiary education was much less a community setting due to students having to get part-time work to keep eating.

In 1997 the PC screen reader technology faced a serious hurdle when workplace computers switched from the old "DOS" operating system to Windows which assumed the PC user could point the mouse at the correct control on the screen. "JAWS" (Jobs Access with Speech) was being piloted by the Royal Society for the Blind Adaptive Technology Unit and I went in once or twice a week to master the skills.

This was a wise move because one Saturday morning In August 1997 Joel woke me to tell me of a half time Disability Services Officer job being offered for two years by Salisbury City Council to develop its Disability discrimination Act Action Plan.

I responded sleepily saying that it was too far away. But Joel was ready for that and with his timetables and street directory showed me that it was only a two bus route and 80 minute journey each way. I applied and was short-listed, this being the fourth short list I had made in four months.

On a rainy September day after school finished he guided me to the interview. It was one of those interviews that moved from question and answer into a discussion about how Salisbury City Council could best develop a sustainable DDA Action Plan.

I was appointed to the role then promptly found out that my 0.5 19 hour per week position didn't give me enough hours to attract Commonwealth funded workplace modifications which I would need to purchase JAWS screen reader and some admin support to deal with printed documents.

It is a measure of how good the City of Salisbury was and is that management increased the hours to 20 per week. The Commonwealth Government support became available and my employment became viable.

In my post-appointment interview my support needs were discussed with my manager Pru Blackwell, along with managers from Human Resources, Information Technology, building management and traffic management. What an employer the City was in 1997!

I was given opportunities to act for my manager when she was on leave, with 18 staff to care for plus other projects. Council increased my contract to five years, made it full-time and then made the "Access Officer" position permanent. During my first year I was appointed as a Workplace Representative for the Community Services municipal office staff for the Australian Services Union.

I was given management responsibility for two small disability inclusion programs funded by the SA Government and in late 2003 was seconded for 3 years for two days per week as Social Development Officer for the Mawson Lakes Joint Venture between Salisbury City Council, the SA Government and Delfin Lend Lease.

All this would have been impossible if not for on the job support through Interwork Ltd (one of the Disability Employment Services funded by the Department of Employment and Workplace Relations).

This support has included paying an extra four hours per week salary for a most capable administrative support staff who works part-time for Council's Library Service. No technical challenge fazes Joanne Odegaard who has been working with me since late 1997. Even today some e-documents are so visual in layout that I still need her PC and optical scanner skills to make them intelligible. With her support I have developed a number of Power Point slide shows which illustrate for sighted colleagues the range of accessibility projects delivered by Council.

### **Fast forwarding to 2011**

Cathy and I now live in our own house in Salisbury North (a mid northern metro suburb of Adelaide). The house design was selected mainly by our daughter and her best friend / cousin Anna when they were 13 in 1999. The house is on a block of land selected in the "Salisbury North Urban Improvement Project" area by Joel in the same year when he was 16.

Cathy volunteers in a number of crèches and continues improving her grasp of the international language Esperanto. I am still working for the Salisbury city Council as its Access Officer and have been a member of the SA Minister for Disabilities' Advisory Council since 2007. In 2009 I won the National Disability Award for the Local Government category and was appointed one of six Disability Community Leaders for the 2011 International Day of People with Disability.

Cathy and I are part of the worldwide Edmund Rice Network which has developed around the (Catholic) Christian Brothers and which works from a base of becoming spiritually centred, recognising the strength of the feminine within us and in the Jewish - Christian story, and working towards social and environmental justice.



Lucilla is now a dietitian with the South Australian Department of Health working in the northern suburbs. She is living at home and saving for her next (third) overseas trip with friends and female cousins to see her favourite music performers).

Joel is Senior Development Planner for the Town of Gawler and with his partner Megan live in the house they have built in the main street of Gumeracha. (Joel, coming from a family without a car, became SA's inaugural Youth Ambassador for Road Safety in 2007 and with the other state's Youth Ambassadors participated in the first United Nations' Youth and Road Safety convention in Geneva in April 2007).

At work we have just completed "Beyond the Ramp" Council's new "strategic inclusion planning framework" which will embed the principles of the United Nations Convention on the Rights of Persons with Disabilities and the National disability Strategy 2010 -20 into Council's corporate planning system and day to day operations.

### **Not allowing current information technological limitations to limit my capabilities**

My career hasn't developed much since 2006. Part of this is due to a "web of exclusion" which is much more complex than a few communication access barriers. Even the national employment reforms of the last 4 years don't address many of the difficulties experienced by people who are blind or vision impaired in getting a job and once they do in getting on in their career.

I can cut through a few threads in the web but there are a lot more and often hard to understand holding me back. From 2007 – 2009 I allowed the limitations of my info. Tech. access to get to me and I used a lot of my long service leave as sick leave in those years.

With great support from my manager Pam Pindral and other members of her Healthy Ageing and Access Team I now can accept that this is just how it is and I try to deal with it. But I am frustrated that there doesn't seem to be serious research into employment stories such as mine to start to understand the different threads in this web of exclusion.

Until this research is done and acted on I believe that people who are blind or vision impaired will continue to be under-employed and even when employed will have a lower trajectory in their career development than their abilities warrant.

There have been many days when I was frustrated by the gap between the screen reader's capacity in a world where more management software is being used but is inaccessible for screen readers.

But then I reflect on the times when Cathy and I were young and poor parents and realise that focus on the frustrations of the present don't get me anywhere. The reality is that for all the technological shortcomings what I am doing is absolutely extraordinary.

In South Australia there is little on the job IT support for vision impaired or blind PC users and almost no peer support network for people across the workforce entry to exit spectrum. For someone without a communication related disability the prospect of working in such isolation and with limited technical support would be daunting.

As I learned along with Cathy in our young parenting years there is much more that is good about everyday than there are frustrations. I believe that becoming part of a network of other people dealing with similar challenges is something I should have done long ago. I also believe that my focus at work is shifting towards the great team and management I have and the small as well as large achievements day to day.

### **My life isn't all about employment and blindness**

But my career flat-line since 2006 also reflects choices I have made ever since the early 1980s. I rarely took work home (until the last couple of years now our children are in their own careers and one in his own relationship and house). I could be much more IT savvy if I had spent time working at home on these skills over the last twenty years. I chose time with Cathy, Joel and Lucilla and am happy to accept the lower career development which flows from this.

### **First generation inclusion requires sustained research**

I believe that a better research and development effort by Government would have made the choice between family time and info tech upskilling less necessary. The only reason for IT upskilling would have been to work my own individual way around the web of communication exclusion that continues to prevail.

So I have used the latest version 13 of the JAWS (Jobs Access with speech) PC screen reader to write this story (I started training on JAWS 2.0 and first used JAWS 3.0 when I commenced at Salisbury City Council).

I will advocate for better research into the on the job experience of people with vision impairment and blindness, which honours our first generation journey and that of our managers, colleagues, support workers and families.

These experiences are just too important to let happen without serious research into making it better for the second generation. I will also work for a peer support network for screen reader users before and after they are employed.

### **A final reflection: disadvantage, relative privilege, parenting and society**

Being partially and later totally blind has been a significant factor in being out of the paid workforce for 11 of the 31 years I have wanted to be employed. Although being blind has had its advantages through the former means test free pension I believe that the parenting this enabled us to provide for Lucilla and Joel has contributed more to society than we have taken.

But the huge unemployment levels for people who are blind or vision impaired remains. In 2007 Vision Australia, in its submission to the National Inquiry into the Employment of People with Disability and People with Mental Illness revealed:

- a 34% unemployment rate of people who are blind or vision impaired with postgraduate qualifications (like me) and who are looking for work
- a 63% unemployment rate across all people who are blind or vision impaired and looking for work.

This story is just one of the hundreds across Australia which could have been told by people who are blind or vision impaired. There are thousands of others with different impairments but all of us are fairly near the first generation of people living with disability who are entering the general workforce.

Our experience is a vital resource for Government and the community sector to learn from. The generation of people coming into the workforce this decade, especially women, Aboriginal people and new arrivals may be condemned to experience the same web of exclusion we have strived to cut through.

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