

Michael's Story

Michael told his story during a conversation between the researcher and himself. The conversation was recorded and transcribed.

Introduction

Work has always been important to me. I saw that work was a quite defining in society. I believe it defines whether or not people have respect for you and respect for your abilities or whether they tend to see you as being a burden and so I've always ensured that I have been a person who was contributing to the community as a whole.

I'm 63 years of age. I was born with Muscular Atrophy. I have multiple diagnoses' including Charcot-Marie Tooth syndrome (CMT)¹.

CMT² can be anything from weakness in the ankles through to impacting on the far extremities of both the arms and legs as has occurred for me and the impact can also at times be very mild with a person exhibiting only a weakness in the ankles that results in regular strains or sprains. At times CMT can impact hearing which I also experience.

Following a workplace accident in the early 1990's I have used wheelchairs for mobility on a fulltime basis for over 20 years

Education and learning

I've always been a prolific reader. With spending most of my youth in hospitals reading was a great thing for me because in the 1960's there was no such thing as schooling in hospitals. My learning to a great extent resulted from my reading books on my own when in hospital or convalescing at home. I continue to have a great interest in reading and I'm very omnivorous in that I read everything. It doesn't matter if it's a label on a packet or whether it's a history book or an autobiography, I read constantly to increase my knowledge.

¹ Charcot-Marie-Tooth disease (CMT) affects the peripheral nervous system. The nerves of the limbs gradually stop working properly and this leads to wasting of the muscles that are served by those nerves. The muscles of the ankles, feet and hands are often most affected.

I attended 14 different schools in the time I was doing my schooling and I missed something like about 4 years where I wasn't in schools and yet I still achieved my Higher School Certificate at a level that I won a scholarship to go to New England University. Unfortunately I was precluded from taking up the scholarship because there was a requirement on me to pass a medical examination and the doctor who did the medical considered that I did not have the medical health and physical capabilities to attend university fulltime.

Marriage and family

My wife and I were married in 1975 and will celebrate our 40th anniversary in 2015. We have 2 sons and we have 7 grandchildren. My sons were tested as young children and I was excited to find that the syndrome had not been passed on to them.

My father and grandfather had CMT and we understand my great-grandfather also had CMT and that the syndrome impacted each of them differently. CMT didn't have a significant impact on my father until his fifties but he had to retire early when it started to impact his hands. I experienced the impact of CMT from three years of age but didn't grow up fearing CMT would negatively impact or restrict my life.

Having disabilities has at times had a significant impact on my relationship. I was able to do a lot of the chores around the house until the early 1990's when I stopped being able to do things like mowing the lawn and that type of stuff. These days my wife certainly does quite a number of things that I assume probably don't necessarily occur for other women in relationships such as heavy lifting, house maintenance and things like that.

A Home of our Own

We purchased our first home back in 1978. I have always been employed and in order to have a full career I moved around a lot with my employment so we have had homes in various places throughout Victoria and NSW.

The current house that we live in we purchased in 1997. I have had it modified so that I can get in the front door but instead of having ramps I got it done in such a way that most people wouldn't recognize that they're walking up a slope and coming to our front door. I have always tried to make things fit in so that it's least visually impacted. Living in the house

itself the primary change would be the accessible bathroom and turning the main living area into an open space rather than having a number of rooms.

Employment

I commenced working in 1970 with a firm that later became Price Waterhouse. I worked with them as a taxation consultant and an auditor for a number of years and went into what was Telecom Australia, now called Telstra in 1974. I started there in Human Resources and then went into their Finance section and spent something like 13 years as part of their Local Operational Management Team. I was one of the members of the Regional Executive for country Victoria.

With the Accountants I used to do quite a lot of travel because a lot of my clients were pastoral clients requiring my travel to various small country towns. Later with Telstra I covered country Victoria and primarily worked out of offices in places like Ararat, Bendigo, Shepparton and Benalla, that is north-eastern Victoria and the western districts of Victoria. I enjoyed the travel particularly as I generally drove on my own and it gave me independence. That's always been the case - driving's been very, very important to me in terms of providing me with independence and also putting me on an equal footing with everyone else. As a matter of fact most people found that they were unable to keep up with the workload that I was able to get through.

I'm currently working as a consultant. I worked as a Director of Disability and Home Care with Family and Community Services in New South Wales until the end of last year. The decision was taken last year by the government that the department was going to move away from direct service provision and so that was my reason for leaving. I shifted to consultancy work where I could be involved with direct service provision.

Barriers and obstructions along the way

Unfortunately there have been times when I tended to find that there were barriers and blockages. They are even greater than what they were in some other times in my life. For example with schooling I found that the support was amazing from teachers and quite often to the point where I had to say "Thanks but no thanks.

Inclusion and exclusion

I have a strong understanding of inclusion and also of how we quite often are not included. The fact that you might be sitting out in a community or living in a home in the community or the fact that you may be in an office doesn't actually mean you are a part of or included in the workforce or community.

I include myself in my community. Throughout my life there have been a lot of different barriers and things that could obstruct and exclude me, e.g. I was recently in Adelaide and I found that the physical access barriers there were rather 'over the top'. There were restaurants where they said that they were accessible and I turned up. I was with a group that I was doing my training with and we were told that we had to go out and down the long hill and wander around in the dark of the night down the path to eventually find an accessible toilet which was about 300 metres away.

When we went to another restaurant, the staff didn't know how to use a chair lift and the accessible toilet was packed to the ceiling to the point where it would have taken them a good week to clear it out if I had wanted to use it. Rather than getting angry, I prefer to try and educate people by talking to them about what they could have done or what they could do in the future. I have travelled to South Australia a number of times and am surprised that its buildings and businesses have such poor physical access.

The future

If at all possible I want to be working through until my late 70s. Yet it is my experience that I am encountering more barriers and particularly with organisations that are working with people who have disabilities. I can see that in my 60's I will have to revisit all of the internal strengths of overcoming barriers that I dealt with from my mid-20s through to my mid-40s. I think that although our current society promotes inclusiveness for active older people and we see advertisements of the 65-year-old running and doing their gym work it is unfortunate that people who are using a wheelchair or crutches for mobility don't fit the current image of active ageing. Often we are exposed to a double negative about ourselves.

Other people's perception

I do see that the younger generations are very accepting and inclusive, accepting someone who has a disability as part of their community and acknowledging that they have skills. My boys both work in the human services field and have always just seen the fact that they have a Dad with a physical disability as part of the norm rather than the exception.

As a Regional Manager and Director of Disability I had over 1,000 staff who reported to me across western New South Wales and the majority of those were 'hands on' workers in the community. I found that the staff were more likely to have a yarn with me, to consider that I would understand their situation, and they wanted to gain knowledge from me about how to work with other people. Interestingly there was greater acceptance from frontline staff of me being a manager who had a disability. Not only was there acceptance but I believe staff saw my disability as being a positive for me when carrying out my role.

My experience has been that people often understand you have been through the hard stuff and see you as being someone they can talk to about difficult things. Working in the disability field and in the aged care field I find that the clients and the families of clients are very much more likely to sit down and have a yarn with me. There is certainly an expectation that I will do more so that means when you don't have the budget or whatever there is at times probably more distress for clients or families when I tell somebody that I can't provide them with something they are looking for because they know I will have exhausted all other possibilities before I come back to them. I consider it very important to build an honest relationship where people know that I'm doing my darnedest to get them what they need.

I continue to have a great ambition for what the NDIS may do for all people with a disability but I am also concerned that many of the organisations out there may actually restrict opportunities and have a negative impact on how the NDIS will be implemented. It concerns me that we are saying that people have choice when they are given the money without ensuring there will be various suppliers of goods or services. I am fearful that with lack of choice in regional areas the possibility the control over your life (as a person with a disability) starts to diminish considerably.

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Over the years the majority of my working life has been working in commercial business rather than the human services provision. I've worked a lot as a manager for Telstra, wineries, etc. At Telstra I was Manager of Operations which is operated from a profit motive perspective. And yet I found that there was greater acknowledgement of my skills and contribution to the organisation (with less concern that I had a disability) than what I encountered when I finally went to the human services side of things. Unfortunately, I think that quite often in the Human Services area people who have gone into management roles or other roles (such as a counselor) have come from the perspective of persons with a disability being a client they are providing services to and generally somebody who would need a lot of help, rather than from the perspective of a person living with disability as an independent functioning individual. No matter how much service providers may talk about 'person centred service provision', I believe the view able bodied managers have of colleagues with a disability is very blinkered and that often the input of managers with a disability often encounters deaf ears in the boardroom.

A blinkered vision of person centred care

The first thing about being person centred care is that other people working in the field need to listen and then they need to have an understanding of what it is that they've heard. I can just give you a simple example if you like: As the director I had a number of managers reporting to me and the example I am about to outline is not unusual. On one occasion I had a manager who advised that the branch was ceasing a service for a client. When I discussed the situation trying to understand the reason for the decision I heard that the workers providing the service considered the client had become aggressive and too difficult to work with.

The person, the client, happened to be a lady who had previously been a business proprietor and also a very successful professional person who had MS. The lady had physically reached a point where she generally needed to use a wheelchair for mobility and was requiring some personal assistance with her various personal care requirements. On further discussion I came to understand that, on more than one occasion, after the client had been sitting waiting a number of hours requiring assistance to have her shower the care

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workers arrived at the clients home late in the morning and, as the care workers were working to a tight schedule requiring them to quickly move on to the next clients home, they needed to rush the lady into the bathroom and wanted her to walk into the bathroom quickly with their assistance.

I understand the lady, the client, as part of her routine had a preference for ambulating independently, while using a walking aid, to the bathroom and she pushed them away when they moved to physically assist her to the bathroom. As a result of what had occurred the care workers complained to the manager that the client was being physically aggressive toward them.

I find it very disconcerting that managers with staff providing personal care services are unaware of how important independence and dignity are to their clients and are often unaware of how disrespectful and demeaning a simple action such as rushing a person through their personal care routine can be to someone who is trying to maintain their last small piece of self; which includes self worth and self respect.

We don't have enough people out there talking about personal experiences, talking about the positives of their achievements. For me to be able to say that I've been employed for over 45 years full-time I think is important; the fact that I have been a manager of various organisations since I was 25 years of age - so almost 40 years as a manager - but then able to move from organisation to organisation and from industry to industry.

I don't believe that I'm a "one-off" or unusual!

There must be so many stories, examples, out there in business and life in general that as advocates for persons with disabilities we need to get through to the entire community, particularly I think through to the decision makers whether that be somebody who's a senior manager in an organisation, whether it's somebody who's a director, somebody who's an architect or an academic!

All of these stories need to be put in front of the general community and decision makers like our various members of parliament. People need to be exposed to the fact that people living with disability contribute to their community. To date I have been disappointed with the “missed opportunities” of the NDIA... the agency itself for not being the employer flagship promoting the abilities of people with disabilities. While I recognise that as a government entity it has many recruiting constraints it is disappointing that, from what I am aware, few of the people in senior management roles have “true” personal experience of disability.

Unfortunately as a society I don't believe that we are able to see persons with a disability as whole persons who experience and should experience the full gamut of life, emotions opportunities and responsibilities as full members of our society.

Personally I find there is often lack of understanding that how people living with disability might feel about themselves and often the person with a visible disability is overlooked in deference to their companion who may not have a visible disability. For instance, I might pay at a register after having purchased something and the attendant will hand the change back to my wife. I have had instances where I put in the pin for the plastic and the attendant actually starts to hand the plastic card back to the person who is with me rather than to me.

Over the years I have attended a number of different conferences as a senior executive where I have had managers or directors from other organisations make the assumption that I must have been at the conference as a 'consumer' rather than as a service provider. Not all that long ago I had one chap come up and pat me on the head and ask me how I was enjoying the conference.

My belief is that if people at the top are acting and behaving inappropriately it absolutely always seeps all the way through to those staff who may be providing personal care and support: In situations like that the organisation may have careworkers with the technical skills, knowledge and ability to complete their tasks but it is important for management to

be aware that the mindset of workers when delivering a service as important if not more important than their skills and technical knowledge.

Expectations

For me having had a disability right from a young child I grew up in a large family with a Mum and Dad who expected me to achieve and who expected me to do everything that all others could do and so I guess there was no such thing as “Michael doesn’t have to do that because of”. There was always an expectation right from the word “go” that I would complete my schooling, I would get a good job and I would contribute to the family. Those expectations became a part of me and I believe I have fulfilled them.

For example, I used to compete in the running races at the small schools I attended. I always competed in the age group running races and usually at the schools parents stood down one end and held a rope across the finish line so the competitors could breach the tape. I used to compete in my age appropriate race and as I said the parents would pick the rope up and hold it across the finish line. After everybody had gone through they’d pick it up again and hold it up. One of my ambitions for the entire time I was at primary school was that I would get to the finish line before they had the opportunity to pick up that damn rope for a second time. I guess that has been my attitude with many things, I just keep on having a crack at it until I succeed according to the personal goal I set myself.

I am not unique there are plenty of people who have resilience. I think it’s also a case that there has always been someone in my life that has been a positive influence. When I have encountered challenges or obstacles and then gone back and spoken about them with my family, my wife, my friends or my colleagues not once have they said “Oh that’s terrible” or tried to find an excuse for me not to succeed. It’s always been a case of “we know you can do that” or “we know that you’ll get there.” I think having a positive voice around you is what helps to build personal resilience.

In building a career and maintaining my employment I always look for a way to demonstrate what I can do. For instance I won a job as Human Resource Manger when I was with Telstra. The men who were to be my managers hadn’t been on the selection panel and
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hadn't met me. I turned up at my work place and although I have only been using a wheelchair on a permanent basis since my accident in 1994. On this occasion back in 1975 I had temporary need to use a wheelchair and consequently was using a wheelchair for mobility when I met the person who was going to be my boss who advised me that he couldn't have me working for him because I might fall out of my wheelchair and hurt myself. Rather than using the complaint system to force the District Director to allow me to take-up my appointment as Personnel Manager I went worked my way through further selection processes and became the Finance Manager.

Over time proving that I wasn't a liability I not long after the refusal became an Operations Manager. A few years later there was a vacancy coming up for a senior national management position. By that time the chap who told me he was worried I would hurt myself working had become so impressed with my work that he stood up at a meeting where all the senior national managers were in attendance and made an announcement that he believed that I should be the first person considered for that position because of my skills and abilities.

Based on my life experiences I have found that you often have an opportunity to demonstrate your abilities to people by quietly doing your work well rather than making a scene or causing a fuss.

The influence of 'people who've been there and done that'

Because I've spent a lot of time in hospital I spent a lot of time speaking with older people who 'had been there and done that'. I spoke with guys who have been through the war and had come out the other side and chaps who had various physical disabilities but had still managed to make it in very dark times and they're talking about the 1940's and 1950's . I believe it's a case of listening to people and I guess taking on board a lot of their spirit. I don't know if such an opportunity is available to very many people. Quite often through my life I have been aware that if I wanted to use my disability as an excuse to not achieve or to not try to do things many people would have been very accepting and happy for me to do that. However, I consider that throughout my life I have benefited greatly from having people around me who believed in me and pushed me so that I always had the attitude and mindset of "You can achieve" and "I have achieved". Sitting down with, listening to and

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learning respect for older people who had been through the mill and had achieved things with their lives had a very strong impact on me as a young person.

For example when I was with the firm of Accountants the senior partner who was my boss on occasion spoke with me about his father who had been one of three foundation partners with the accountancy firm and had originally been a marine engineer who lost his left arm in a machinery accident. My boss told me a number of stories about his father who had retired including a story about how his father was playing bowls and had won the regional bowls championship. His father in order to keep himself balanced when playing bowls used to keep a lead weight in the left-pocket of his jacket and had to deal with a protest because the non disabled player who was the runner up to him in the championships had protested that his father had an unfair advantage by having the lead weight in his pocket. Stories like that have enabled me to understand that when you are competing in the “real” world your competitors give no quarter.

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