Trevor's story

I was born at Port Pirie in 1955. I was11 months old when I was diagnosed with Cerebral Palsy (CP). Before that, I was thought to be a “lazy baby”. My parents had no knowledge of CP, and found it hard to accept there was no cure. They were advised to “Put me into the Home for Incurables and forget about me”. Thank you Mum and Dad for not taking that advice! At different times they took me to a chiropractor, a hypnotherapist and a faith healer, but no miracles!

When I was almost three years old, my mother had a younger child to care for and was also expecting another, so it was suggested for her sake that I have a six-week trial at Woodville Spastic Centre, during which time they were not to visit me. This was very upsetting for everyone. After a couple of months, although I was given treatment every day, I became very stiff and jerky in my movements and was unable to sit up alone. My parents decided it was best for me and everyone else if I lived at home. They moved from Port Pirie to Campbelltown, and I lived at home and went to Woodville daily. Dad was a carpenter around Port Pirie, just trying to make ends meet. I’m the fourth youngest of six kids in the family.

When I was young, Mum and Dad allowed me to go off with whomever I wanted; do what I wanted to do with them, and they were very supportive with all my committee work. I always had transport provided by Mum or Dad. I was always encouraged, and the way they would *always* get me there. They’d go to fundraisers with me and stay there and help me. Dad took me to play chess for Ashford school at John Martin’s every Friday night. He would make sure I was always on time. He’d stay, and take me back home after I’d finished. I was lucky that way. I didn’t have to worry about transportation a great deal.

My parents were ingenious in finding ways to help me enjoy various activities. My father used to help me feel like I was mowing the lawn. The mower was placed in front of my chair with my hands on the mower handles, and my father would push from behind - very heavy work for him, but it made me feel involved.

At one time, for some childish reason, I decided to run away from home, and before long my wheelchair got stuck. The way I moved was to push the wheelchair backwards. Suddenly to my surprise I was moving *forward*! I looked over my shoulder and realised my Dad, who wasw driving on his way home from work, was pushing my chair in front of the car!

Dad also used to take me out fishing in the boat when we stayed at our shack in Balgowan (on York Peninsular). The nose of the boat would be right out of the water, we would be ploughing through the water, spray would be flying, and the boat would be banging against the waves. I had a sense of freedom and adventure that nothing else could give me. Later I realised how brave and understanding my father had been to take me out in a boat. Because, if anything was to happen, like the boat capsizing, tied to my wheelchair and later on a bus seat, I would go straight down to the bottom if anything went wrong.

One particularly crazy escapade of my youth was when my then brother-in-law gave me a ride as a pillion passenger on his motorbike. We were staying in the family shack and away from usual traffic. I was thoroughly secured on the back of the bike - held on with many ropes - leaning up against the rider; we went on a scrub trek for a few miles. I think my brother-in-law may have been glad to get back in one piece as I kept leaning to one side, and he had to lean the other way as a counterbalance.

When I was about 10 I was the president of the Thunderbird Club. There were three of us at Woodville Spastic Centre who were right into the Thunderbirds and so we started up this fundraising committee called the Thunderbird Club. We got recognised by *TV Guide*, who did a story on us. They came down and presented me with photographs of all the Thunderbirds! It was important to have that kind of success and recognition at that age. The Thunderbirds also used to run a stall at the annual Woodville Spastic Centre fete.

When I was 13 my sister taught me to read cursive (which interestingly, never happened as part of my education!). I had a pen pal in Japan and I couldn't independently read his letters so she took up the job of teaching me how to read cursive because that's how he always wrote.

I was interested in science, so at Ashford House School they organised for me to attend Adelaide High School for one session a week. In those days the driver was also my note taker. I had a very big electric chair and all the kids were expected to carry me up two flights of stairs to the classroom! That wouldn't happen now, but I bet those kids will never forget that classmate who was in a wheelchair!

I’ve always been on committees. I was president of a social club for young adults at school. That was purely a social get-together after hours; and I would arrange guest speakers. I was president for a few years. This was my first committee at the age of 18 and that experience showed me I could do committee work and enjoy seeing changes happen because of it. I really think being part of committees or groups gives you a certain belief in yourself and an identity. I feel privileged to have been invited to join numerous Boards and Committees, as well as attaining seven or more Ministerial Appointments at state and federal levels, over a 30 year period.

In the late 1970s I got involved in things such as the state branch of DPI (Disabled People International) and a club for people living with physical disability. I was one of the inaugural members of that club. This was before we had access cabs, and we had one person in the whole state running a taxi service for people living with disability. One of the guys in the group convinced Peter, the owner/driver to buy a whole lot of buses or vans and provide a cab service to people living with disability; which became “Handibus” – no longer around.

After I left school I felt I faced an uncertain future, but managed to gain employment with the Regency Park Centre (RPC). I was appointed the Contract Room Manager. My role was assessing and training young people living with disability to be work ready. I would develop ways for people to adapt work processes and a set of targets for their work schedules. I learned a great deal, both about people and about the workplace. I wrote a submission for a Work Assessment and Skills Program to be run in the community instead of it all staying within a specialised centre. The program was designed to provide people with severe disabilities the chance to expand their range of skills. The submission was successful.

At RPC, outside my work role, I was also the instigator of the Link Disco, which was held every other month. I recognised that all these people living at RPC would love to go to a disco! Around the complex was a whole community who required a cheap disco to go to. I got two or three people together on a committee and got a friend who was the DJ to come down. I started the disco for people living at Regency Park, but after the first year I was able to open it to other young people in the community. It was the first “integrated disco” in South Australia. The disco continued to be successful for four more years.

My first taste of independent living was at Fokus Housing at Mile End. I am a real advocate for something like Fokus housing because it taught me so much. Fokus was a independent training and transition house. It was supported by the South Australian Housing Trust and run by Fokus Society. I left Fokus to move to Old Treasury Lane, which was where I began living independently. Meals on Wheels assisted me to do this, and I used their service for 16 years; it was the difference between me living independently or needing my mother to cook all my meals!

It was at Old Treasury Lane that I discussed the need for self managed personal care services with Maurice Corcoran, another resident living with disability. Together we wrote up a constitution and obtained funding from the Commonwealth Government for the first such service in the state - Disabled Independent Persons SA (DIPSA). I managed to obtain more funding for another services, that shared administration costs with DIPSA - SA Independent Lifestyles (SAIL). My role now involved recruiting, screening and managing a pool of Personal Attendants; recording performance between the parties and; reporting regularly to the funding bodies in order to obtain ongoing resources. Those two services are now combined into and called Enhanced Lifestyles.

I was also involved in the devolution of the Rua Rua Nursing Home. This meant I had to go out and assess houses for practicality and suitability for prospective clients. This was a very interesting experience, which subsequently led to a direction for my future employment. Realising that my best chances of employment lay with myself, and not wanting to just push paper from one side of the office to another for the rest of my life, I set up my own business, HC Harrison Consultants. I worked as a Disability Consultant in Access Auditing and Training, and have subsequently successfully tendered for many jobs with State Government departments and local government agencies. Private architectural firms have also contracted my services from time to time for access advice, as have individuals seeking reports to be presented to local government for home modification.

It is my belief that the reason some people living with disability find it hard to be inspired to live independently and find the courage to gain open employment is because we often lack high expectations from those around us. There isn’t a lot of expectations placed on people living with disability. I was lucky I always had encouragement. I was allowed to make mistakes and learn from those mistakes. I firmly believe that if anyone is allowed to make mistakes they can learn from that experience. I believe that today we've gone too far the other way - denying people the chance to learn and strive, fall down and get up again. Where's the "dignity of risk" gone? It's all been lost to occupational health and safety! My philosophy is if you're not thrown in the water you will never learn to swim. Today if someone says they want five hours of personal support a day then that's what they get. I was originally given three hours a day for my personal support and I am still working with three hours 40 years later.

If I had a professional around I wouldn't have tried and learnt half of the stuff I have. Because as a consumer who receives the support of personal attendants, I am the non-legal employer of that personal attendant. No-one's training the consumer in how to work with the personal attendant. Now, are we being set up to fail? I've been calling for funding to train consumers for 20 years, and nobody's listening. But if we are really and truly serious about putting the consumer in control, we've got to take the power away from the so-called professionals and give it to the real professionals - the consumer. Consumers are the only ones who know what their disability is, how it impacts on their lives, friendships, relationships, learning and employment and therefore they know what they can and can't do. In other words they are the "experts of their abilities" and know the best way to achieve the task. I've only ever worked in open employment, when all the professional assessments suggested I would "only ever work in sheltered workshops". This is what I mean about low expectations!

I am very proud that I stayed away from sheltered employment, and even better - that I ran my own business for almost a quarter of a century!

I'm all for the NDIS! It's the first and the only chance we're going to get (in my lifetime) the Australian Government to really change and revolutionise disability services. I think we should grab it with both hands, and make it work. And it concerns me that not all consumers are seeing this as a great opportunity to make sure it works for all. Every citizen benefits from the NDIS, people living with disability, their families, support mechanisms and also all those people who don't have a disability now, but might in the future – NDIS will be there for anyone with significant disabilities. The NDIS is the best way for us to get a change. Okay, it might not be the best thing that we've got going for us at the moment, but if we get in there, we've got a chance of getting a system to work for us. If we stay with the old system, it would never be able to turn around at all.

However, I am concerned about the way information about the NDIS has been communicated. If you haven't got a computer, and you're not online, how do you know about it? I've had a real problem with the Every Australian Counts campaign - the whole thing is IT based. I see that through the business we've done recently, up in indigenous communities (APY lands), and wonder who's talking with/for them, or talking about them, or looking at their situation? There are many people who don't have easy access to internet communication.

In 1999 I got married to Jill Fowler. Jill had been working at Disability Action Inc, and at one time I suppose I was her boss, being on the Management Committee!

Jill came to work in the business in 2000. Later we put on another staff member on a part time basis, and we were really busy working for the next decade. Some of the highlights of that work were some national firsts, like auditing the Botanical Gardens in the city and Mt Lofty; over 30kms of Adelaide CBD streetscape audit; Roseworthy and Waite University Campus; three new buildings at Flinders University; advising on access to and within the PBMS building at UniSA.

Our lives are spent in each other’s company a lot, we enjoy going away in our camper trailer and bush camping. We’ve been to central Australia, to Melbourne via the Grampians, West coast and Eyre Peninsular, the Flinders Ranges – up as far as Lyndhurst and are looking forward to our next adventure. We love the mallee, and have a small wooden cabin on 63acres/24hectres where we have campfires, wildflowers and wildlife.

We recently closed business after 24 years. We decided to close-up for two reasons; firstly we were tired of the constant need to keep advising the construction industry about something that had been a legal requirement for a decade and secondly business had slowed down – with the GFC and many cost cutting exercises by local and state governments, little access work was around. To revive the business would have meant a whole new marketing strategy like when I first started out and I just didn't have the energy.

I now have a family of my own; something which I had hardly hoped was possible, although I am a naturally optimistic person. Just before Jill and I were married we bought our own home and had adaptations carried out to make it habitable for both of us, Ned our dog, and our visitors. One of my criteria was to have a shed for woodworking and general repair, the house came with a double garage and is now full of woodworking machines. My stepson Isaac lives in Melbourne with his wife, and every now and then Jill disappears for a week to visit! Through Jill’s daughter we now have two beautiful grandchildren whom we love to have visit. Zaine was born in 2000 and Cinnamon in 2007.

I consider I have much happiness in my life … and there’s still more to come!

In some instances, stories may have been edited for practical purposes, but care has been taken not to change the author's 'voice' or the integrity or purpose of the narrative.