Whose History ???

Vic Finkelstein

Disability History Week, Birmingham, 10th June 2002

> Live all you can; it's a mistake not to. It doesn't so much matter what you do in particular, so long as you have your life. If you haven't had that what have you had?
> [Henry James (1843–1916) The Ambassadors.]

The meaning of life

On a warm sunny afternoon in Durban, South Africa, I took one of those decisive steps in life that we are not often privileged to make at an early age. At that time I could have expected to complete my schooling, then obtain a junior trainee job, perhaps in commerce or the motor industry, probably meet and marry my partner for life, have children, then perhaps see my grandchildren starting on their journey into life before I retire and then say farewell. Instead of these predictable, 'normative', course of events, and without knowing it at the time, my choice resulted in an amazing bouquet of surprises – entirely unpredictable friendships, world-wide travel, diverse careers, loving relationships in a delightful family, and the honour of being given a little role in helping to turn one small but enduring part of the world upside down.

At the age of 16 years it never occurred to me that I was not supposed to start on this particular adventurous voyage; that I was not supposed to see life as meaning 'taking part in innovation and social change'; I was not supposed to see 'being human as meaning taking control over one's destiny'. I was not supposed to defy the destiny that was mapped out for me by my parents, the community and the culture into which I was born.

My life should have ended that eventful day, or as everyone in my family thought, 'my life was ruined', because on that day I broke my neck while pole vaulting at my school sports ground; on that day I left the world as I was and then re-entered as a 'disabled person'.

The meaning of disability

I can still vividly remember the forlorn faces gathered around my hospital bed staring down at me, saddened by the hopeless future they all accepted had now closed-in on me; wanting to offer comfort but not knowing what to say or where to look. Being paralysed, never to walk again, becoming ‘wheelchair-bound’, as the non-disabled ‘shoe-bound’ fondly refer to us, is an unquestioned end of ambition, life’s normal expectations and joie de vivre. This is what I have now come to know as the ‘Christopher (Walkman) Reeve’ syndrome – the absolute conviction that not being able to walk is the pits, a disaster, social death. Becoming a person with a disability is being branded with a stigma as surely as any slave carrying the mark of an inferior station in society. This, I was expected to accept and suffer for the rest of my life. But nobody seems to have caught on that ‘stigma’ is only the sanitised prejudice of able-bodied bigots who discriminate against disabled people, blame us for being treated differently, and then expect us to cope with the stigma imposed on us!

A few months later the orthopaedic surgeon decided that the Durban hospital was no place for a white South African to deteriorate and I was shipped off to *Stoke Mandeville Hospital* in England. A year later after endless exercise in the physiotherapy department, basket making in the occupational therapy department, being bounced into taking part in the Stoke Mandeville games (where I have to admit I won a medal for South Africa), getting uproariously drunk in the South African style on the female ward at my girlfriend’s birthday party, seeing snow for the first time and being bewildered by British culture (which I still don’t understand), I came home.

I returned to the school where my new life had started simply because I had already passed the highest academic level available at the local ‘special school’. I can still clearly see my first day arriving back at school as a sizeable number of the six hundred students stared on interestedly at the boy in a wheelchair. I was being pushed by my brother who, like me would rather be anywhere else than there. He did not look where he was going and tipped me onto the ground. That was how the ‘reality’ of the able-bodied world hit me as I made my first re-entry into their environment. Absolute humiliation, absolute dependency, absolute difference and absolutely no adaptations made on my behalf.

Not being able to walk, not being ‘whole’ is surely Superman’s nightmare. Able-bodied people seem to have been indoctrinated into believing that underneath the imperfect bodies that make us human they are really *Superpeople* and those of us who deviate from this image are ..., well, ‘freaks’. But Superman is a fantasy and somewhere along the course of history non-disabled people have come to believe that the fantasy is real, and the reality is a mistake.

Lifestyles

In my new life I soon learnt that non-disabled people’s culture expects us to behave in two opposite ways at the same time – we are expected to be cheerfully brave in the face of universal prejudice while at the same time we are expected to be stoical and accept the inferiority imposed on us by the personal tragedy we are said to suffer:

I was staying in a hotel while researching my Masters degree and a very drunk guest flopped into the seat opposite me at the breakfast table. After a moment he said that he been watching me during the past few days and was struck by how brave I was despite my disability. I always seemed quite cheerful. Had he known me he would have realised that this was the surest way to provoke a twisted response! I knew from other guests that he was staying at the hotel while his wife was away (not knowing how to cook for himself) and that he was unhappy about having to go to work every day. Reacting to his stereotyped assumptions that I was not employed I replied that I was relaxed because I did not have to face the stress of daily work, I had no family worries and no bills that I had to earn money to pay. At the hotel I could read, listen to the radio and meet new people – in short, for me life was one long holiday; whereas he had to put on a brave face, go to work and worry about his job! This seemed to touch a very raw spot and he now accused me of being the opposite of what he had just praised me for! Now he angrily burst out that I was a coward, a sponger and a bum. He never spoke to me again.

My life seems to have been a record of defying expectations: I didn’t go to special school, I didn’t become a salesman or motor mechanic, and I wasn’t law-abiding:

At university I got in, as they say, with a bad crowd – revolutionaries who wanted to overthrow the apartheid state. As I was dragged up and down flights of stairs in inaccessible university buildings and pathways I indoctrinated my helpers with communist ideas – or at least this is what the secret police maintained during my interrogation when I was eventually arrested. How and why I mixed with these outlaws is another story.

Bram Fischer was the General Secretary of the South African Communist Party and had been Nelson Mandela’s lawyer at his trial. When Bram also went underground our role was to provide support. One by one the network of supporters were arrested and when Bram was captured I knew my time had come. During the days and nights of non-stop interrogation by the security police it became clear that I was regarded as an evil invalid who had got involved with political ‘extremists’ as a compensation for disability. General van der Berg, head of the secret police, popped in to see for himself how the interrogation was progressing with the crippled leader of the underground – the stereotype maintained I couldn’t be anything less!

Jail in South Africa was the apartheid state’s university and, as I was moved from one prison to another in response to a partial month long hunger strike and inaccessible cells and toilets, I met and communicated with many prisoners despite being in solitary confinement for six months. Being a dangerous influence I was held under the 180 day detention laws and then refused bail when I was put on trial.

My cell was like a post office tapping away messages on the different walls to people some of whom I knew but most were only names that I'd heard. Bram Fischer occupied the cell above me on the second floor and we comforted each other with messages. He was held in strict isolation with no newspapers whereas at that time I received my daily paper. So every evening I copied out the political and other interesting news in tiny writing on sheets of toilet paper which I folded into a small square. The next day during my half-hour exercise period I concealed this in a crack in the toilet wall, alongside all the other messages that everyone was posting, and Bram collected his mail when he came down to exercise after my turn. Unfortunately he was caught collecting his post and we were shunted into different cells. We never communicated again.

Half-hour exercise in the morning and afternoon was one of the few prisoner's rights that I was still allowed and insisted on having. So twice a day a black prisoner would collect me and push me round and round the courtyard (after I had been to the toilet). This is the only time I have ever been given a free personal helper! No doubt nowadays in the UK I would be charged for this 'excellence in care'!

It seems to me that when the state sees the need there is no difficulty in providing personal assistance for disabled people but while I studied architecture in Durban and psychology in Pietermaritzburg and Johannesburg I had to rely on friends and charity for assistance in negotiating inaccessible environments and teaching practice.

Before leaving South Africa as a political refugee I was given one final and lasting lesson about the meaning of 'disability'. I was served with a five year banning order which limited my 'right' to unrestricted travel, education, employment and social gatherings in South Africa. But, as every disabled person knows, as a social group we are denied these 'rights' anyway! The banning order made very little difference. I have to ask the question, then, is there some kind of connection between being branded a dangerous revolutionary who is a threat to the state, and being branded as a disabled person and some kind of threat to non-disabled people's culture and social values?

Role models

For me arriving in Britain was a liberation, a new beginning. Despite all the daily restrictions imposed on disabled people in this country I felt far less trapped than I had ever felt in SA. Here I met my future wife who introduced me to the services and facilities that were available. She also persuaded me to attend meetings and during one of these gatherings we met Paul and Judy Hunt. Talking to them was a revolution in thinking and suddenly the segregation imposed on black South Africans by apartheid and the universal segregation imposed on disabled people seemed identical.

Aside from the year I spent at *Stoke Mandeville Hospital* I never had the opportunity of associating with other disabled people. My heroes and role models were all non-disabled people. In a great rush soon after arriving in Britain, in addition to Paul and Judy, I now also met up with Ken and Maggie Davis, Ken and Anne Lumb, Dick Leaman, Brenda Robbins, Anne Rae, Kevin Hyett and Sian Vasey, to mention just a very few; some of whom joined together in setting up the Union of the Physically Impaired Against Segregation (UPIAS). We all shared common experiences of systematic segregation and prejudice, and we all believed in campaigning for an integrated society. Like most people I had started with a negative perception and understanding of disabled people and now, amongst my new-found friends I began a process of reworking my role models.

Using the language and experience of apartheid I wrote a carton series for the Link television programme that Rosalie Wilkins presented on Sunday mornings. Overcoming apartheid involved turning the racist world upside down and in my story disabled people living in an apartheid-like village become the dominant group, design the social and physical environment exclusively for themselves and then oppress people who deviate from themselves. The story ends with alliance building for a society in which everyone can participate as an equal citizen.

As an emancipatory organisation UPIAS opposed all forms of oppression and we insisted that our group should be open to people with different physical impairments (despite comments about UPIAS now). Focusing on society as a whole we avoided becoming a ‘single-issue’ group and we opposed segregation in housing, education and employment. We also advocated alliance building with other disability and non-disability organisations. By the late 1970s and early 1980s UPIAS members were working with a wide range of people in different local and national organisations. At that time I personally worked closely with Stephen Bradshaw, Elsa Beckett, Peter Large, Mike Oliver, Julie Pellow, Rosalie Wilkins, Francine White, Francis Hasler, and many others on various tasks, including setting up the British Council of Disabled People (BCODP).

When BCODP joined the Disabled People’s International (DPI) I learnt that the disability community was world-wide and that we were all changing our personal sense of identity and goals in life. This movement actively challenged some of the very basic and deeply held stereotypes and prejudices of non-disabled people.

When I applied for a psychology course at university I was confronted by a professor who put forward a string of arguments why I, as a disabled person, was unsuited to studying psychology. When I applied for a teaching course at university I was confronted by a special education inspector who put forward a string of arguments why I, as a disabled person, should not get involved in special education – she maintained that it was not a good idea for disabled teachers to teach disabled children because we get too involved! On that basis, I countered, women should not teach girls: her argument collapsed and she did not openly oppose my entry into that profession.

But human diversity has a habit of confounding exceptions and I was warmly welcomed and supported by Vida Carver at the Open University (OU) when she recruited me to what I believe was the world’s first course in disability studies. This course was clearly different to the existing medical and rehabilitation courses and in an important way provided ‘establishment legitimacy’ to our emancipatory wishes. The course provided a nation-wide platform from which stereotypes about disability could be questioned and new perspectives on services and lifestyles could be raised. It also gave disabled people an opportunity to study and tutor a course which had started to make real sense of their lives.

I now found myself actively engaged with UPIAS, BCODP, DPI and the OU, as well as other local and national disability associations. In the light of this activity I came to recognise that the ‘soul’ expressed by all these groups could be found in the growing sense of identity.

This was no less than an emergent culture of disabled people and I joined with Seona Reid and Geof Armstrong from Shape London, Sian Vasey from Artsline, Anne Rae and myself from UPIAS, Ashley Grey from Graeae, and Joan Greening and Pius Hickey from Strathcona in forming a steering group to set up the London Disability Arts Forum (LDAF) to support and promote our own culture. Its particularly pleasing to see this culture flourishing and having such a great reception here in Birmingham at the ‘Disability History Week’.

Emancipation

If there is one thing I have learnt in travelling through life’s adventures it is that the cultural values now worshipped by non-disabled people and imposed on the rest of us are flawed. The deeply human values cherished by disabled people are where I believe humanity needs to go, otherwise it will destroy itself. It seems to me that mainstream culture has horribly lost touch with reality. People running round and round a track in circles, or kicking an air-filled leather bag up and down a grass field, is not just regarded as healthy enjoyable fun but held up as the height of achievement!

With such an unreal culture that worships physical perfection it cannot be an accident that euthanasia has once again been raised to a level of legitimacy in able-bodied society to deal with suffering and difference. In contrast the aspirations and culture expressed by disabled people over the past thirty years is an affirmation of human validity in all its forms.

We have repeated over and over again, and at every level in society, that disabled people are not just ‘dependent’ beings, a drain on resources who need to be made ‘normal’, institutionalised or provided with perpetual ‘care’ (however ‘excellent’ such provision might be). Society needs emancipated disabled people because non-disabled people will depend on us to take a leading role in humanising the health and community support services and in returning mainstream culture to its fundamental roots – the sanctity of human life.

I do not see this ‘Disability History Week in Birmingham’ as just our history, but rather as another advance to a higher level in the civilisation of human beings.

When I went pole-vaulting at school that fateful day I left behind one destiny and replaced this with another more fulfilling, more rewarding and more human than I could ever have hoped as I made my way under a sun that we all share.