

THE SEVEN IMPAIRED SAMURAI: LIFE OPTIONS FOR THE DISABLED

Peter Beatson

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PREAMBLE

After mulling over my own experiences, first as partially sighted then totally blind, after conducting sociological research into the lives of other blind people in both France and New Zealand, and after musing on the history of disability in general, I began to perceive a number of distinct patterns emerging. It seems to me there are seven life options that have been imposed upon people with disabilities, or – more rarely - that we have chosen for ourselves. These seven options can be thought of as a series of evolving historical stages, each representing an advance on the one before. This is not to say, however, that the first options have now been discarded on the rubbish heap of history and that we are now living in a higher and more enlightened state of social evolution. On the contrary, all seven are alive and well and living in New Zealand today. Some of the earlier ones may appear barbaric, but beneath the surface civilisation of the contemporary world still lurks a considerable amount of barbarity in society's treatment of people with disabilities.

The fault does not lie with able-bodied society alone. Disabled people on occasions collude in and contribute to the disabling stereotypes which prevent us from living totally fulfilled existences. Thus the following satirical pen portraits are intended not just as indictments of a heartless world, but also as reminders of how we may ourselves unwittingly connive in the lopping off of parts of our own personalities.

But enough self-flagellation. A moment ago, I promised you a taste of barbarism. Without more ado, let us turn the global clock back to the dawn of human life and confront the first and most primitive solution devised by society to solve 'the disability problem'.

OPTION 1. THE FIRST AND FINAL SOLUTION

A parched hillside in the cruel morning light. A vulture circles over a small, naked, human form.

No - not entirely 'human'. It is a baby that has been born blind. It was left on the barren rocks early this morning to die. As the sun climbs towards the zenith, its cries grow thinner and weaker. At noon they cease. The vulture drops to the earth and shuffles towards the motionless form, its bald head outstretched.

An ice field in Greenland. A bear, its breath foul with the hunger of long hibernation, stops and sniffs the air, then lopes purposively forward. A shriveled human figure watches it advance, eyes dilated.

No - not entirely 'human'. It is an old woman whose painful, arthritic hands are no longer of use to the tribe. A useless burden, she has been left on the ice to die. Her lips move in a silent prayer as the bear reaches her.

Germany. The Third Reich. A Roman Catholic hospice for the mentally defective. A doctor in a white coat slides a lethal needle into a human arm.

No - not entirely 'human'. The arm belongs to a man with oddly mongoloid features and the intellectual age of a two-year-old. His existence is an insult to the purity of the Aryan master race. The doctor briskly crosses a name off a list, re-fills his syringe and moves on to the next bed.

'But all that,' you expostulate, 'was long ago, far away. Things like that don't happen nowadays.'

Oh no?

New Zealand. Today. A pregnant woman, tears running down her cheeks, is signing a form as her doctor and partner watch compassionately. She is signing for the termination of pregnancy, putting an end to the gestation of a human embryo.

No - not entirely 'human'. Scans have revealed the unborn child has spina bifida. Everyone agrees it would be inhumane to bring it into the world, as well as a drain on taxpayers' money. Tomorrow it will be sucked out of her womb and discreetly disposed of.

Again New Zealand. Again now. A woman lies anaesthetised on a hospital bed as skillful surgical hands close off her fallopian tubes. The human eggs she carries inside her will never now be fertilised.

No - not entirely 'human'. Some of those eggs may carry a tainted gene that will cause

blindness. Everyone agrees it is better that the woman should remain childless than bring a blind baby into the world.

And again New Zealand. Again now. A young man sits in a wheelchair while his mate leans over him holding a glass to his lips. It contains a large shot of whisky and more than enough sleeping pills for the job on hand. As the immobilised figure gulps down the potion, his mate is already thinking of the telephone call he must make to the police and the trial which will inevitably ensue. The court will be sympathetic; he will receive only a token sentence. He will have pleaded that he was not committing murder, but mercifully putting a fellow human out of intolerable suffering.

No - not entirely 'human'. The man in bed used to be a potent lover, mighty sportsman and successful young executive until he broke his neck in a diving accident. Everyone agrees it is better to be dead than drag out a pathetic lifetime as a quadriplegic.

I called this paper 'life options for the disabled'. What I have been sketching, however, are not life but death options, and they are usually not options at all but the first and final solution devised by the able-bodied for 'the disability problem'. Don't let us breed. Kill us before or at birth. Encourage us to commit suicide. As a last resort, stick us in the gas ovens.

Although somewhat lacking in cultural sensitivity and political correctness, this option has the great merits of being economical, tidy, unambiguous, total and lasting. The disabled, it is agreed, are a burden to society, a nuisance to their family, a drain on economic resources and a misery to themselves. Above all, they offend the Darwinian notions of the survival of the fittest, and the eugenic dream of evolution towards a pure human species, perfect in body and in mind. The disabled are biologically degenerate. They are holding back the march of humanity to racial perfection. We are, in short, subhuman. If Hitler's lead is followed, the disability problem will be solved in a generation. Quite simply, there will be no more people with disabilities to worry about.

OPTION 2. THE HUMAN VEGETABLE

The only snag about the tidy and total solution to the disability problem just outlined is that many people appear to have a certain moral squeamishness about taking the lives of their fellow human beings. This may stem from religious principles, embodied in the notion that all human life is sacred, or may be grounded in secular humanist notions of inalienable natural rights, amongst which is the right to life. If such scruples prevent the able-bodied from disposing of the disabled once and for all, what then can be done with us?

Let me tell you about a young blind woman I heard of when I was visiting a paradisiacal South Sea island a few years ago. She had lived out all her life in one small, dark, enclosed hut. She was not deliberately mistreated. She was fed, washed and clothed each day by members of her family. But she had never been educated, never allowed to walk in the open, never encouraged to participate in the normal round of social intercourse. Consequently she still had the intellectual and emotional age of an infant, and even bodily she was underdeveloped.

Her family had been motivated by two sentiments when thus shutting her off from the rest of society and thereby depriving her of full human status. First, there was family pride: 'We care for our own'. Second was family shame: 'Nobody must know there is a disabled person in our household'.

The case of this young woman, while extreme, is not untypical of the second life option available to people with disabilities both past and, unfortunately, present. If moral principles will not allow us to be exterminated, the next obvious solution is to keep us out of the way in segregated hothouses reserved for human vegetables. In asylums, hospitals, hostels, institutional homes, half-way houses and private households throughout New Zealand and the rest of the world, innumerable disabled cabbages sleepily idle away their lifetimes until the worms return them to the humus from which they regrettably sprang.

Conditions in the ghettos vary enormously. Some are like prisons or worse, the inmates exposed to everything from total neglect to downright brutality. Yet let us not get too paranoid. There are many institutions or private homes where people with disabilities live cozy, secure and tranquil existences, surrounded by a close-knit community and looked after by humane and well-intentioned caregivers.

Vegetables are not necessarily victims. We may be given a modest living allowance by the welfare state, supplied with talking books by the Blind Foundation, have outings and concerts arranged for us by IHC or CCS, be waited on hand and foot by guilt-stricken family, and even be photographed for the local paper with Royalty patting our heads or squeezing our soft, vegetable hands.

Nevertheless, even under the best hothouse conditions the fact remains that a cabbage is a cabbage. We are not encouraged to get an education, because whoever heard

of a well-educated vegetable? We are not encouraged to get a job, because whoever heard of a vegetable working? We are not expected to get married and have children because whoever heard of a vegetable head of household? We are not expected to participate in local or national politics, because whoever heard of a country run by vegetables? And we are not - most certainly not - expected to educate, organise and agitate on our own political behalf.

In short, we never 'rise to the challenge' because we are never challenged. What is more, hothouses being what they are, we seldom develop the imagination or energy to challenge ourselves. Indeed, disability may be a glorious excuse for opting out of responsibility for our own lives.

Meanwhile, able-bodied society gets on with its own affairs untroubled and complacent. It has demonstrated its respect for the sacredness of human life and the inalienable rights of the individual by keeping us alive. It has also ensured itself of an easy conscience by tucking us up in hothouses where we are seen only by our guardians and are therefore of no concern to the citizenry at large. What cozier solution could there be to the disability problem?

OPTION 3. THE BEGGAR AT THE GATE

Hang on a minute! By keeping us locked up in hothouses, are we not wasting some of the economic resources locked up in those cabbages? We cost quite a lot to keep alive. Surely we should make some contribution to our own upkeep?

Viewed correctly, disability can be a lucrative, exploitable resource. Most of the major world religions enjoin the giving of alms to the needy as a path to salvation or a way of knocking off a few incarnations - and who could be more needy than people with disabilities? Even secular humanists are often afflicted with a streak of philanthropy which has them diving into their pockets for deserving causes. And who could be more deserving than people with disabilities? Hey mate - a pair of empty eye sockets, a couple of stumps, a hump on your back and you are in business!

Admittedly, begging has often been a last ditch necessity forced upon the disabled by lack of other sources of income. Even in affluent societies like 19th century Britain, if your family could not care for you and you did not fancy the poorhouse, begging was your only recourse. This is still the case in most third world nations today. I am told it is not uncommon in many overseas countries for parents deliberately to mutilate their children in order to enhance their street cred as deserving beggars.

But let us not be too complacent about the difference between 'them' and 'us'. Although the number of people with disabilities in New Zealand who beg on their own account are fewer than in, say, Calcutta, we are all subjected to annual bouts of mortification as our organisations launch media appeals and door-knocking campaigns on our behalf. Even in a welfare state, the disabled are all beggars at the gate. My guide dog, for instance, came to me courtesy of begging campaigns, not my right as a citizen.

However, not all people with disabilities regard begging as a form of humiliation. When doing research in the 1970s into the life of the blind community in Marseilles, I made friends with a cheerful street beggar called Pierrot who worked down by the docks, strategically placed near a bar. He passed his days agreeably enough, squeezing an old accordion he had never learned to play and wheezing out popular songs as unspeakably French as the smell of garlic and Gauloises. When he discovered I was a student, he scolded me roundly. Why, he wanted to know, was I living a parasitical existence reading books when I should be out on the street earning an honest living like him? He also, incidentally, was rather lofty about blind people working in the local sheltered workshop. He could earn in a day more than they got in a week.

Begging, then, can be lucrative, is not necessarily a source of shame and is a necessity even in the welfare state - if by 'begging' you include public appeals made on our behalf. Furthermore, it is one step up from the life of the human vegetable. You have to be active and resourceful, you are out there on the streets mixing with mainstream society and you make an independent contribution to your own and your family's livelihood.

Even so, although you are 'in' society you are not 'of' it. In order to earn a living you have to make a spectacle of yourself, like the dancing bears, wild men from Borneo and freaks who used to throng medieval fairs or tour with the great travelling freak shows of the 19th century. You are not an integrated member of society. You are The Other - the object of the gaze. You are not a human subject in your own right. Members of the public may slip you a dime, but they would not want you in the family, any more than they would want their daughter to marry a dancing bear.

OPTION 4. SEGREGATED SCHOOLS AND WORKSHOPS

Paris. The late 18th century. A certain M. Valentin Haüy is sampling the exotic wares of one of the traveling freak shows popular at the time. Amongst the wild men from Borneo and dancing bears, he encounters a group of blind men who amaze the crowds with their capacity to identify coins by touch.

Valentin Haüy is a lateral thinker. If the blind can do this, perhaps they are capable of a great deal more? With help and encouragement from the sighted, might they not even be educable? Might they not, too, be taught certain basic work skills that would allow them to earn a modest living for themselves, rather than relying on charitable hand-outs, or on marketing themselves as freaks?

From these Parisian musings grew the first school and subsequently the first sheltered workshop for the blind. Special schools and sheltered workshops for people with disabilities marked a great leap forward in our social evolution. They allowed us to take our first hesitant steps out of the world of perpetual dependence and into the main stream of cultural and economic life. We were granted the right to learn and to labour.

Let's not be too ecstatically grateful, however. Those first steps did not take us very far. Our places of education and work were still shut off from the rest of society. In the special schools, we learned the basics of literacy and numeracy, but little by way of serious academic attainment was expected of us. University education was still an impossible dream. We simply shuffled out of the segregated classroom into the segregated workshop.

In the workshop, our deft little fingers were put to work making cane baskets, weaving rugs, plaiting ropes, producing coat hangers, packing boxes and the like. Good, honest, artisan work, replete with the dignity of manual labour, but offering little by way of intellectual stimulus.

Did I say 'dignity'? Perhaps I was getting a bit carried away. The people who ran the workshops told us we were performing 'real work', but we, the inmates, started having some niggling doubts as the years, the decades, then a century or more rolled by. We realised that there were some basic contradictions coded into the very foundations of the philosophy of sheltered work. It tried to do too many things at the same time, got its prosthesis in a twist and fell flat on its face.

First, the workshop purported to be a genuine production unit – an enterprising little factory competing for contracts on the open market. But to do that, it clearly needed to employ, train and retain top notch employees. You cannot achieve productivity and quality unless you have good workers.

That brings us to our first Catch-22. As well as being production units, sheltered workshops were also supposed to perform a rehabilitation function. This was not so

important a hundred years ago, but became increasingly significant since World War I. Rehabilitation is a major 20th century fad, replacing the older social philosophy that fostered segregation and dependency.

What the philosophy of rehabilitation meant for sheltered workshops was that they had to train workers then, when they developed the confidence and skills, encourage them to fly the nest and find employment in the open workforce. In other words, those running sheltered workplaces were required to cut their own economic throats. To be productive, they needed good workers, but to fulfill their rehabilitative responsibilities they were expected to push their best employees out into the big wide world.

That is not the end of the Catch-22s, however. The sheltered workshop also had a third function - namely, to provide what we might politely call 'occupational therapy' for those who were so extensively disabled or lacking in confidence and motivation that they were unlikely ever to find a job in the open labour force. In short, the workshop was there to provide a pastime (albeit a rather dull one) for people who could not survive in the lean, mean, free market. This was a real headache for managers of sheltered workshops who took their entrepreneurial role seriously. They were supposed to be running real factories, yet were also obliged to provide recreation for workers who, through no fault of their own, were only marginally productive.

And what if you were a worker rather than a manager? You were told about 'the dignity of labour', but as you swapped experiences with friends in the open work force you discovered they enjoyed certain basic rights denied to you. For a start, your wages were much lower. In fact, 'pocket money' might be a better term than 'wages'. Moreover, you did not have the same basic rights of all other workers to negotiate your terms of employment. You could not join or form a union, and could not organise and agitate for better pay and conditions. Most certainly, you could not strike.

The crux of the matter was that you were working in a strange, hybrid organisation - a social welfare factory or charitable enterprise. It was doing you a favour by giving you a job in the first place. Consequently, you had no basis on which to throw your industrial weight around. Let's face it - you had no industrial weight to throw.

These were the kinds of subversive thoughts which flickered through our empty minds as down the generations we applied our deft little fingers to cane baskets, hemp ropes and wire coat hangers. Two hundred years ago, M. Valentin Haüy rescued us from the traveling freak show. We were given education and employment. But the education equipped us for little but the sheltered workshop, while the latter provided us with the shadow rather than the substance of real paid work. Moreover, both took place within a disability ghetto. This was the 19th century solution to the disability problem, but one which continued to thrive well into our own epoch. We have only recently walked out from under the shadow of segregated education and employment in which philanthropists, with the best intentions in the world, imprisoned us.

OPTION 5. NORMALISATION

I shall usher in my fifth life option for people with disabilities with a perhaps unexpected name. Henry Ford.

Now, we all know that Ford was the great grand-daddy of industrial mass production - the man who invented the assembly line and the standardised motorcars which rolled off it in their millions. Ford, however, did not just produce cars. He also produced jobs. In doing so he inadvertently ushered in a new epoch in the social evolution of the disabled.

The point about jobs on a Fordist assembly line is that they have been so simplified and standardised they can be performed by just about anyone, including the severely disabled. All you have to do is stand or sit all day, repeating the same simple gesture - turning a screw, welding a joint or whatever. You do not need many brains, much education or even a fully functioning body for such tasks. You are simply an appendage of the vast industrial process.

Ford was greatly enthusiastic about the implications of his new factory system for both the disabled and the able-bodied. It liberated the former from dependence on charity, inactivity, begging or undignified sheltered work. At last they could be out there in the open labour force, earning their daily bread like real people. On the other hand, Fordist production liberated able-bodied workers from machine slavery. Why, Ford asked, waste the skills and energy of the able-bodied on mindless repetitive tasks which the disabled could perform equally well?

Ford was the pioneer, for both good and ill, of the 20th century solution to the disability problem. We can call it normalisation, integration, assimilation, rehabilitation, mainstreaming or inclusion. The idea is simple, reasonable and humane. Push people with disabilities out of their ghettos and integrate them into normal society. Abolish special schools, sheltered workshops and segregated residential institutions. Get disabled people living in the community, attending mainstream schools and working alongside the able-bodied in real jobs.

This is accompanied by a terminological reform. You stop talking about 'the handicapped' or 'the disabled' as a stigmatised category set apart from normal society. Instead, we are just 'people with disabilities'. Better still, we are just plain 'people'. The fact that we happen to be deaf, paralysed, blind, chronically fatigued or whatever is to be politely overlooked by others and played down by us. Like Ford's cars, we are mass produced, standardised, normalised social products, fit for general consumption in a world that puts a premium on conformity.

Nothing wrong with that, you may well say. Surely most of us do want to be normal, to be accepted as human beings on equal terms with others? It is not much fun always being 'one of them' in a society which places high value on being 'one of us'.

Okay - fair enough. Most of us want to be thought of as normal. There are, however, a few drawbacks to the social philosophy of normalisation, some related to the way it is put into action, others to the principle itself.

For a start, the theory of normalisation or assimilation is not always matched by its implementation. 'Get the disabled living in the mainstream community', they cry - but forget to put into place the financial and human resources necessary for the transition from the closed institution to open society. Is it really integration to be dumped from a segregated rubbish bin into an open gutter?

'Get disabled kids out of special schools and into normal ones,' they cry - but again omit to supply the financial and human back-up to make it work. Is it really integration to be dumped from an under-challenged academic backwater to an under-supported mainstream classroom?

What about assimilation into the open labour force? Vocational case managers pride themselves on their quantitative successes, but sometimes look less hard at the quality of their achievements. 'This week we have placed X number of disabled people,' they cry - but don't always enlarge upon the kinds of jobs they get. The result is that a large proportion of workers with disabilities end up in what has been termed the 'secondary labour market'. It comprises jobs with low pay, little prestige, poor working conditions, few career opportunities, no overtime or perks and little expected by way of initiative, creativity or responsibility. The jobs are also frequently part time and/or temporary. In a word, disabled workers when not unemployed are frequently under-employed. They have jobs but not careers.

Now let's look at the philosophy of normalisation from another direction. Although the integrated disabled are no longer in the ghetto, does that mean that we are necessarily accepted on equal terms by the able-bodied with whom we rub shoulders? Does physical integration into a classroom necessarily change the attitudes of able-bodied kids towards the disabled? Popular myths to the contrary, hard research suggests it does not. Again, does having the intellectually disabled in their midst make members of the community automatically more tolerant and accepting? Experience proves not. Although you may technically be one of the boys on the shop floor or one of the girls in the office, does that guarantee your acceptance as 'one of us' by able-bodied bosses, colleagues or clients? On the surface you may seem to be accepted, but just below the surface a thousand little cues hint to you that, while colleagues tolerate you, they would be more comfortable if you were not there.

All these, however, are just practical details. There is a bigger issue of principle at stake - an issue of identity and of the philosophy of 'difference'. Maybe you do not want to be normalised at all. To be assimilated, integrated and mainstreamed, you are required to renounce what in existential reality is a major part of your personality. You might not like being disabled, but it is not something which is going to go away by being politely ignored. Indeed, you may actively take pride in your disabled identity.

To explain this, let's digress a minute. The philosophy of assimilation was practiced on the Maori in New Zealand for several decades after World War II. They were accepted into mainstream New Zealand society so long as they abandoned their Maori identity and became brown Pakeha. In the 1970s, however, they rebelled, re-asserting their right to proclaim their difference from Pakeha. Maori identity was now something to be proud rather than ashamed of.

Are there not parallels here with the situation of the disability community? If to be normal means pretending that you are not really blind, deaf, paraplegic, mentally ill, etc, or at least pretending that it does not matter, you may feel the game is not worth joining. No matter how strenuously you play at being normal, the irreducible fact remains that you are different. The attempts of well-intentioned rehabilitationists, placement officers, mainstreamers and the rest may get you out of the disability ghetto but leave you in limbo. No longer segregated, not really integrated, you are neither fish nor fowl nor good red herring. Perhaps, you ask yourself, the normalisation game itself is the red herring? Why not turn necessity into a virtue by proclaiming pride in your disabled identity?

OPTION 6. SUPERCRIIP

Mild mannered, visually challenged Clark Kent sneaks into a telephone box. 'To hell with integration,' he mutters to himself. 'To hell with being just one of the boys on the shop floor. To hell with being normal.'

The telephone box door swings open and out leaps a figure sporting blue leotards, a scarlet cape and red knickers. Up, up and away! Is it a bird? Is it a plane? No! it is a plucky little cripple ostentatiously overcoming his disability as he soars into the rarefied ether of megastardom. Supercrip!

There are two paths you can take if you want to be a disabled celebrity. The first I shall call 'the Richard III syndrome', the second 'the Helen Keller syndrome'. The former involves fighting your way to the top of the able-bodied pecking order in spite of your disability. You are a hunchback, but like Richard III wade through rivers of blood to be crowned in the kingdom of the normal. You are epileptic, but like Julius Caesar conquer Gaulle, Britain and Cleopatra. You are deaf, but like Beethoven you pour out musical masterpieces. You are blind, but like Milton write epic poetry. You are schizophrenic, but like van Gogh give the world paintings of unsurpassed power and beauty.

Alternatively, like Helen Keller you can turn the fight against disability itself into a career. You win gold medals at the Paralympics, gain awards for your services to the deaf, write autobiographies about your courageous battle to overcome blindness, or you gain celebrity status through your one-person crusade to remove the stigma attached to AIDS.

Like all those who dance in the spotlight on the high wire, it must be admitted that you are a bit of a narcissist. After a few whiffs of public acclaim, you grow addicted to unstinted admiration. If more than a week goes by without your being told how inspirational you are, you start getting twitchy, craving for another reassuring shot of applause. It must also be conceded that you are not all that eager to be associated too closely with other disabled people. How can you stand head and shoulders above the crowd if you are surrounded by a motley horde of the commonplace deaf, blind and lame who block the view?

Your hogging of the limelight may give rise to envious mutterings amongst disabled plebeians who have not climbed to the same dizzy heights. They grumble amongst themselves about elitists, tall poppies, show-offs and the like. You remain quite imperturbable, however, since you have the perfect response to accusations that you are getting above yourself. It is not for you alone, you insist, that you are ambitious to be the first Miss Universe with spina bifida, the first paraplegic to dance with the Royal Ballet or whatever. Not a bit of it! On the contrary, the term 'role model' trips easily and frequently off your tongue. You are single-mindedly pursuing your brilliant career so that younger disabled people should be inspired by your example to go forth and do likewise. As a role model, it is not fame for its own sake you seek but the inspiration it will give

those who follow in your footsteps or wheel prints (though not too closely, you hope).

Am I making you sound a bit smug and self-satisfied, Supercrip? If so, perhaps I am being a bit unfair. After all, you would not be up there on that pedestal if able-bodied people had not built it in the first place, then hoisted you up. What I am getting at is that when society is not trying to exterminate us, shut us up in asylums, segregate us in sheltered workshops or normalise us, it has a perverse tendency to attribute to us special powers and gifts, seeing us not as sub- but supra-normal.

In many traditional religious societies, for instance, certain types of disability were thought to be of supernatural origin, or to put their possessors in touch with higher spiritual beings. They were regarded as mouthpieces of the gods - prophets, seers, oracles and the like. Even in secular societies, the disabled are frequently surrounded by an aura that sets them both apart from and above the able-bodied herd. They are typically depicted by modernist writers as holy innocents, their affliction making them touchstones of authenticity in an unauthentic world. In spite - perhaps because - of their marginality, they are indefinably 'better' than members of corrupt, mainstream society.

Even when literature portrays us negatively as villains, we derive an odd, upside-down kind of celebrity status through our notorious naughtiness or deformity. Captain Hook, Long John Silver, the phantom of the opera, the hunchback of Notre Dame, Frankenstein's creature and the rest are megastar monsters. We shudder at their infamy, but nobody could accuse them of being 'just one of the boys'.

Literature and legend apart, many disabled people also have acclaim forced upon them as they just go about their everyday lives. You are stopped in the street and told how wonderful you are. Why? Well you can chew gum and steer your wheelchair in a straight line at the same time, can't you? A miracle! Or, if you are blind, you are informed by just about every sighted person you meet of your incredible memory, superhuman hearing, tactile sensitivity and remarkable insight into human character. Oh - and let's not forget the endearing sense of humour which is the hallmark of all us plucky little cripples.

Thus bombarded with bouquets, is it any wonder the accolades sometimes go to our heads and we end up thinking that we are indeed wonderful? Even if I do not really believe it, why should I - a very ordinary Clark Kent - disillusion the admiring multitudes who are convinced I am supernaturally gifted? If there is a bit of chic and a dash of romance attached to being disabled, why not cash in on it? And who knows - perhaps I really am a superhuman seer or (more fun) subhuman monster?

There are just one or two drawbacks to the Supercrip role which may give me pause. For a start, it is hard to keep it up. Dancing day in, day out on the high wire is a strenuous business. It can lead to exhaustion, even burn-out - not to mention the danger of falling. The applause is intoxicating, true, but intoxication is usually followed by a hangover. It might be safer to remain one of the mild and wondering herd than risk the lows that follow the highs.

There is another problem facing the aspirant Supercrip. I might call it 'charisma overload'. The currency of megastardom is getting devalued because, quite simply, there are too many Supercrips around nowadays. You who were yesterday's disabled prodigy grind your teeth in fury as you hear about yet another blind person flying solo from London to Auckland, or yet another intellectually disabled person winning Mastermind. There are so many cripples jostling one another on the summit of Mount Everest, it is harder and harder to capture the media's attention. The competition is growing tougher, the scene more crowded and the general public getting a bit bored with disabled celebrities.

Finally, there is a nasty, niggling doubt which assails you in the middle of the night as you pursue your brilliant career. This career is based on your amazing courage in overcoming your disability. The emphasis, of course, is on the word 'overcoming'. Yet as you go up to receive the award for deaf tiddlywinks champion of Eketahuna amongst popping flashbulbs and whirring cameras, that old doubt starts niggling.

Perhaps it is not on the 'overcoming' but on the 'disability' that the press and public are focusing. Were you able-bodied, would anybody care about your tiddlywinks prowess? Perhaps you are not so much overcoming as feeding upon your disability. Take away the disability and you would once again be just nice, dull, mild mannered Clark Kent.

High above Metropolis, a figure in blue leotards, red knickers and a scarlet cape loops the loop, laughs mockingly and disappears into the rarefied ether reserved for compensatory dreams of grandeur.

OPTION 7. THE RADICAL ACTIVIST

Leader: 'What do we want?'

The masses: 'Freedom!'

Leader: 'When do we want it?'

The masses: "Now!"

Radical activists are in many ways the polar opposite of Supercrip. He dances the light fantastic on the high wire; they storm the Bastille. He is an individualist; they are collectivists. He feeds on narcissism; they call for solidarity. He seeks to stand out from the crowd; they renounce the cult of the personality in favour of a unified social movement whose end is the liberation of all disabled people.

The notion of disability as a social movement or liberation struggle was born, along with other civil rights movements, in the United States back in the 1950s and 1960s, but really only picked up steam after the 1981 Year of Disabled Persons. It bears a strong resemblance to and imports much of its rhetoric from other movements like black power, feminism, gay liberation and even good, old-fashioned Marxism.

Radical activists reject the notion that disability is a personal, medical tragedy which must be coped with as best they can by individual victims and their families. Radicals equally dismiss the idea that it is a welfare problem that can be solved by social engineering on the part of able-bodied legislators, social workers, rehabilitationists and the like.

Sure, disability is a problem but it does not lie with disabled people themselves, but with the structures, processes and attitudes of the wider society. Just as women are the victims of sexism and blacks of racism, so the disabled are the victims of 'ablism' or 'disablism' (we have not quite made up our minds yet what to call it). Nobody denies that living with cerebral palsy, depression, intellectual disability, paraplegia and so on is difficult, but the difficulties are magnified a hundred fold by the physical, organisational and attitudinal obstacles that 'ABs' (able-bodied people) place in our way. The request that these obstacles be removed is not an appeal for charity - it is a demand for civil rights.

Radical activists wage their campaign on two fronts - political and cultural. On the political side, they confront the ablist hegemony with a multi-pronged attack on discrimination, oppression, stigmatisation and marginalisation. They lobby politicians, battle the educational establishment, picket public transport companies, write letters, form action committees, plead, protest and march. Lacking much in the way of economic or political clout, they depend largely upon 'the politics of embarrassment' to advance their cause. Politicians and the public do not like to be seen being heartless to Cripples. Radical activists exploit this moral squeamishness by publicising able-bodied sins of omission and commission. Shame can be a powerful political weapon.

It is not just politicians and the public at large that activists target, however. There are

some scores to be settled within their own organisations. Many voluntary agencies like the Foundation for the Blind, CCS and IHC were in their origins - and to some extent still are - run from the top down by well-intentioned but paternalistic able-bodied people. They operate a kind of caste system with able-bodied brahmins at the top and the disabled untouchables at the bottom. A major element in the disabled social movement has been the rebellion of the untouchables against the brahmins. Disabled militants demand the right to control their own organisations rather than being handed down goods and services from on high.

Still on the political front, activists make strenuous efforts to forge a united federation across disability lines. This is no easy task. All social movements are threatened by a tendency to balkanisation – that is, to divide into disparate, competing cliques rather than standing shoulder-to-shoulder. The drive for Maori unity is impeded by tribalism. Feminism is bedeviled by a proliferation of liberal, radical, cultural, socialist, lesbian and Maori factions. Similarly, the blind, the deaf, the paraplegic, the intellectually disabled and the like tend to define disability in their own terms and to place their particular group self-interest higher than the cause of the disabled in general. Yet for there to be a disability social movement at all, it is essential that inter-group solidarity should transcend in-group parochialism.

So much for politics. Now let us turn to the cultural side of the equation. Just as the Maori and women's movements in this country have insisted that their struggles for equity involve a cultural as well as economic and political dimension, so radical disabled activists proclaim the existence of a distinct disability cultural identity in which they can take the same pride as Maori take in Maoritanga or women in the achievements of female artists.

In some cases the disabled have not had to look too far to discover such a culture. The profoundly deaf, for instance, have a sign language of their own, and the blind possess a tactile alphabet, both known only to an inner circle of initiates. Such concrete instances apart, however, disabled people tend to be a little vague about what they mean by their 'culture'. Sometimes they invoke their repertoire of in-group jokes. More vaguely still, they may lay claim to a special mode of 'spirituality', allegedly generated by their affliction.

We may be a little sceptical about some of the claims made for the existence of a distinct disability culture, but such scepticism misses the real point. What is really at issue is the assertion of a disabled identity over and against the cult of normality prevalent in able-bodied society. Just as radical Maori refuse to be brown Pakeha and radical feminists refuse to live on terms set down by the patriarchy, so too disability fundamentalists withstand the normalisation process. They are not plain, ordinary people who just happen to have a disability – something to be politely ignored or shrugged off with a merry quip. They are not 'people with disabilities' but 'disabled people' – and proud of it.

At the limit, this proud assertion of disabled identity can lead to disabled separatism. Whereas the 20th century philosophy of integration stressed the need to get people with

disabilities out of their segregated ghettos and into mainstream society, extreme disabled radicalism reinstates the old division between 'us' and 'them'. Putting it starkly, disabled separatists construct their own ghetto. There is all the difference in the world, however, between the new apartheid, chosen and implemented by the disabled themselves, and the old apartheid imposed upon all people with disabilities by an indifferent, embarrassed or hostile world.

Now let's turn back from disabled cultural separatism to the radical political activism with which we began. What are its virtues and vices? One thing must be clearly and unambiguously affirmed. If disabled people en masse are to make any progress towards full human status, it is absolutely essential that there should be radical activists in our midst. The history of all hitherto existing societies has shown that no oppressed, exploited, stigmatised, marginalised or trivialised group has achieved acceptance, equality and justice without a struggle. Dominant groups in society do not practice equity spontaneously and from the innate goodness of their hearts. It must always be wrung from them. The working class realise this. Women realise this. Maori realise this. People with disabilities must realise it too. Civil rights can only be won if people are prepared to fight for them.

Yet disabled radicals must pay a price for their militancy. They have to endure the opprobrium of being labeled stirrers, ingrates and malcontents by the able-bodied, as well as by more passive members of the disability community itself. They must burn up time and energy they can ill afford when they also have to hold down jobs or simply cope with the pain, fatigue and handicaps inherent in the disabled condition. They must endure the infinite frustrations of fighting a cause where each victory is small, partial and laboriously won, while setbacks, defeats and the sheer brute inertia of the establishment are seemingly endless.

But there is more. Though they may not themselves be aware of it, the political struggle may diminish their own intellectual integrity and even their humanity. Locked perpetually into the grievance mode, militants live in an over-simplified, black-and-white world where four legs (the disabled) are always good and two-legs (the ABs) bad. Only a thin line separates the glorious freedom fighter from the obsessed fanatic. Years spent fighting discrimination may wither you down to an upraised, clenched fist and angry protesting mouth. Not only do you risk losing the capacity for clear thought and reasonable analysis, Worse, your stridency and sloganeering may generate a backlash against the very cause you are trying to promote. Excessive zeal, untempered by common sense, humour and tolerance, may be more of a liability than an asset to the disability rights movement.

Furthermore, always blaming the system may afflict you with a moral paralysis that makes you incapable of accepting any individual responsibility for your own personality or actions. Every failed relationship, lost job opportunity or personal setback is blamed on the stupidity or heartlessness of the able-bodied establishment, never on your own human shortcomings. In short, you may develop a victim mentality even while you struggle to overcome victimisation.

One final word on the dangers that may beset the activist. It is the word 'co-option'. When you look back over the history of other liberation struggles or social movements, you often notice how yesterday's militant may become part of today's establishment. A stropky trade unionist gets co-opted onto the board of directors of a bank. A radical Maori activist becomes a right-wing politician. A feisty feminist turns into a managerial queen bee. In short, successful leaders may be corrupted by their own success. They justify their new access to power, prestige and wealth by avowing they are continuing the old struggle, inside rather than outside the corridors of power. Yet little by little a gap opens between them and the rank-and-file of the movement. Those at the grass roots begin to wonder whose ends are being served as the former crusader turns militancy into a lucrative personal career.

I am not suggesting that this has yet happened with disabled activists in New Zealand. What I am saying is that if leaders of all other social movements have succumbed to the sweet siren song of the establishment, it is almost inevitable that at some future date certain disabled radical activists will be transformed into an elite of intellectuals, executives and consultants with interests separate from the movement they once led.

The masses: 'What do you want?'

Leader: "The gravy train!"

The masses: 'When do you want it?'

Leader." 'Now!'

PERSONAL CONCLUSION: THE POSTMODERN PRANKSTER

I began this survey in the mists of antiquity, where a vulture was devouring a newborn impaired baby left on the hillside to die. I ended with a disabled elite of intellectuals, executives and consultants chuffing off to the future in the first class carriage of the gravy train. In between, I sketched the historical progression of the disabled from segregated asylums through sheltered workshops to the open labour force, not forgetting the virtuoso displays of the occasional Supercrip.

It would be misleading, however, to assume we are dealing with a steady, upward evolutionary process, in which each stage transcends the one before. On the contrary, all seven options - even those we would like to think the most primitive and inhumane - are alive and well in New Zealand today. Most of us have encountered them in our own lives. We are likely to have contemplated suicide, experienced times of vegetative inactivity, held out our begging bowls for welfare benefits, been shunted off to special schools, made strenuous attempts to be normal, tried out a few struts on the high wire and thrown ourselves into one or other form of militant action.

Well then - which is the preferred path? Obviously I cannot speak for other people with disabilities, but given my druthers which life option would I choose?

The quick answer is that I would not choose any one if I really had my druthers. I would prefer not to be disabled. Since I have no choice in that matter, however, I still would not opt exclusively for any one life path as the final solution to my or anyone else's 'disability problem'. Each has its attractions and drawbacks, but none on its own promises me the two things I simultaneously require - to live a fully rounded life yet acknowledge my disability.

All the alternatives I have sketched are too cramping, one-sided and restrictive. They do not allow for the many potential identities I have inside me clamouring to get out. Therefore I would strenuously resist having any one stereotype imposed upon me and would equally refuse to suggest they should be imposed on others.

So I don't fancy walking always and only down any of the paths I have described? What, then, do I desire? Would it be perverse to say that although I don't want any one of them, I want them all?

Yes, it would be perverse. That's what I want to be - perverse. Perversely plural. I want to be a playful, polymorphically perverse postmodern pluralist prankster. Freedom is all about choice. Why, then, should I not choose to dip in and out of the different disabled identities as and when the occasion or my mood demands?

At times I may feel it appropriate to ignore or play down my disability in order to 'pass' in normal society. At other times I may play it up, linking arms with fellow disabled militants as we sing 'solidarity for ever'. When narcissism gets the better of me, I shall

slip into my Supercrip costume and loop the loop high above the marveling crowds. Yet there is almost irresistible appeal in the image of myself with cocoa and woolly slippers living a quiet, cabbage life on welfare, waited on hand and foot by an enslaved family or dedicated social worker.

Or I may decide to potter off to the sheltered workshop each day to earn a bit of pocket money performing some unexacting manual task and chatting with my sheltered colleagues. Or again, why should I not go down to the city centre with my wheezy accordion, begging bowl and sign reading 'guide dog and three bad habits to support'. Finally, if frustration, pain, exhaustion or the role of the perpetual dependent wears me out, I demand the right to end it all with what dignity remains to me. It is, after all, my life. It is for me to decide when the game is no longer worth playing.

Am I asking too much? Probably - but why should I at least not try? Heaven knows, my impairment has robbed me of so many life options which the able-bodied take for granted. Should I not have the right to improvise freely with the few tunes left me? To the extent of my limited ability, I want to play with my disability, not let it play with me.

AUTOBIOGRAPHICAL NOTE

I was born with a degenerative eye condition and went totally blind in my early thirties. In the 1970s, I wrote an ethnographic doctoral thesis on the blind community in Marseilles, and in the early eighties did a quantitative survey of blind employment in New Zealand. In the mid-1990s, I created the first New Zealand undergraduate course on Disability Studies at Massey University, and founded the *New Zealand Journal of Disability Studies*. I then drew all my personal experience and sociological research together into a major book entitled *The Disability Revolution in New Zealand: A Social Model* (third edition 2004). As well as my work on disability, I have also taught and published on sociology, literature and the arts, and on human-animal studies.