

Life on the Back Roads

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It seemed like a good idea at the time. I was 21 years old, newly married, straight out of university and only months into a new and demanding job, still enjoying the fruits of part-time work in my teenage years that meant I'd been able to purchase a brand-new, bright orange Ford Fairmont V8 with all the trimmings.

My future brother-in-law and I, full of bravado but not as well enamoured with common sense, decided it would be a great idea to leave work on Friday afternoon, drive all night from Sydney to Melbourne where my wife was being trained in airline reservations, to join her and my sister (who had the common sense to fly) for a weekend of partying.

As the sun went down on Sunday evening we jumped in the car and drove all night back to Sydney, where we both faced an early start at work on Monday. We'd had no sleep, and I arrived at work to face an unexpected exam that would determine whether I passed or failed my induction training. I did, but I don't know how.

All that might not sound like such a big deal these days. After all it now takes only nine hours to do the trip, and that's sticking to the speed limit. It's dual carriageway all the way. It's smooth. It's comfortable. And it's safe.

Back then it took 14 hours and it was a shocker. The old Hume Highway was a single lane each way for the most part. There was no divider between the north and south lanes so it was incredibly dangerous. The road wound around avoiding hills, creeks and other obstacles. The road surface in many places was nothing short of appalling. It was like travelling on the back roads of a third world country.

Of course the new Hume Freeway didn't just magically appear. It started out with a vision that was being talked about even before we made our ridiculous trip to Melbourne. Some of it - a stretch around Campbelltown outside Sydney and another stretch just outside Melbourne - was already in place. Plans were drawn up, money was allocated, and over the next 20 years, piece by piece, the

individual sections of road were constructed and joined together, bridges and tunnels were built, mountains were moved, roadside service centres were built, awe-inspiring interchanges that look more like massive works of art were built to join highways to other highways.

And the result? The superhighway we have today has made an arduous, long and treacherous journey into a safe and enjoyable experience for everyone.

For the “average citizen” in the Western world – and increasingly in the developing world – life itself is a superhighway. The Superhighway of Life is just like the new Hume Highway – fast, safe, comfortable. Those who want to travel in the fast lane can do so, while those who choose to take life at a less frenetic pace can travel peacefully in the slow lane. All along the highway people have choices – to pull over at a comfortable roadside service centre to stretch their legs, or to take a different direction altogether ... a new career, a new place to live, a new hobby.

And just like the physical highway, we have invested inestimable amounts of time, effort and money to build that superhighway. There’s a legal system to protect our citizens’ rights. There is a transport system to get to work. There’s an education system to build our skills. And there’s a job to go to each day. When life goes a little off the rails there’s Roadside Assist– a great medical system for those inevitable health “flat tyres”, a bank loan when finances are tough, a holiday to recharge the batteries.

And Citizen Average is travelling that superhighway in a vehicle fit for purpose. He or she is welcomed into the community, and indeed expected to make a contribution. She or he has received a quality education and is ready to make a

productive contribution to society. And the “school of life” – those day-to-day, real-world experiences that the average person is exposed to from early childhood – have prepared him or her, practically and emotionally, to go out into the world.

People with disability are, almost by definition, not Citizen Average. An “average person” can walk. I can’t. An “average person” can see. A person with visual impairment can’t. An “average person” can hear. A deaf person can’t. An “average person” is of average IQ. A person with intellectual disability isn’t. There’s a lot of “can’t” in that – don’t all of these things make a person with disability “less able” than Citizen Average? The term “disability” certainly seems to imply so.

But hang on, how is it my disability (quadriplegia – I use a power wheelchair for mobility) that makes me late for meetings, and not the fact that less than half of public transport is wheelchair accessible? How “able” would Citizen Average be to contribute to society if we took half of the public transport off the road tomorrow? How “able” would Citizen Average be to work on the 30th floor of an office building if the building owners decided to save money by not installing lifts? Or stairs to the front door?

I was at a meeting on the third floor of an office building yesterday which had five steps to reach the foyer. No ramp. In this case there was an alternative (there often isn’t) and that was to go to the back of the building to the underground car park. You wouldn’t believe the number of tradesmen’s entrances, rear lanes, storage rooms, commercial kitchens I’ve had to go through to get where I’m going. To open the car park roller door I had to call someone in the organisation I was visiting, and wait nearly 15 minutes for

the garage door to be opened. Lucky it wasn't raining.

Of course all of this held the whole meeting up, and made everyone less productive. I was late for my next meeting because I couldn't reach the lift buttons to get back down to the car park. I had to wait – inside the lift – for someone to come along to do it for me.

Was my disability the problem here, or was it the lack of universal design principles that would have taken the needs of people who use wheelchairs into account when the building was first designed? Or was it the lack of teeth behind the Disability Discrimination Act which, despite making all of this unlawful, has put virtually no pressure on anyone to fix the access issues? Was it even as basic as the community not thinking it's a priority because, after all, "people with disability just sit around at home all day, don't they?"

And it's not just these individual examples that make it so hard for people with disability to participate. If that was the only building in the world that isn't accessible it would be a different story – life is not perfect for anyone, have you noticed? Shit happens.

But it's not just one building, it's the vast majority of buildings. My wife and I took a walk down King Street in Newtown recently and noticed that 98% – yes, 98%! – of the shops, restaurants and cafes were inaccessible ... most because of a single step that my power wheelchair can't climb. And when we went to catch a bus back to the city, three of the four buses that came along were not accessible.

If all of this practical stuff is not bad enough, it's actually only half of the problem. The even more insidious barriers relate to the emotional effect it has on

people with disability to be treated as second – no, third or fourth class citizens.

At the risk of leaving you, dear reader, with the impression that I'm just an angry old man, may I share with you another example of the disgraceful way we treat people with disability in our modern society?

I sometimes travel from Sydney to Newcastle, the Blue Mountains or Wollongong on the interurban trains. Sydneysiders have come to refer to the ageing rolling stock as the "Silver Rattlers". The carriages are really not bad for their age. They are air-conditioned, quiet, big panoramic windows, I understand the seats are quite comfortable. I'm sure a trip from Sydney to Newcastle must be very pleasant for Citizen Average.

I wouldn't know. I can't get in to the air-conditioned section of the carriages.

To enter the train, Citizen Average steps from the platform into a small, grotty, non-air-conditioned "vestibule" which either contains a toilet or room to store bikes and luggage, then immediately through a narrow door into the main cabin.

Alas, not me. My wheelchair doesn't fit through the door, so I spend the entire trip with the other baggage breathing in the noxious smell from the brakes on the wheels, freezing cold in winter and expiring from the heat in summer, unable to make a phone call because of the noise, constantly being climbed over by passengers wanting to get to the toilet.

It must be hard if not impossible for Citizen Average to understand how this makes me feel. Yes, I can get from Sydney to Newcastle by train, but every time I do so I get angry. Angry that we think it's important that Citizen Average has a

comfortable journey, but not me. Angry that I pay tax like everyone else but can't use a lot of the things my taxes pay for. Yes, maybe I am just an angry old man.

Of course that's just my reaction. I know other people with disability who just accept it and deal with the crap, and I don't criticise them for that one iota. If people with disability complained about everything that needed fixing to welcome them to the Life Superhighway, that's all we would ever do.

The group that really concerns me are those people with disability who just give up. They don't complain, but nor do they just "get on with it". They stay at home. Their fire has gone out. And our society never gets to experience the enormous contributions they can and want to make to help build a better world. It's just plain wrong.

I will never criticise a person with disability for the choices they make about the lives they lead. It's a long, hard, daily grind dealing with all of this stuff, and a person with disability needs to have the willpower of Martin Luther King, the patience of Mother Teresa, the tenacity of Thomas Edison, the problem-solving skills of Einstein, and the hide of a rhinoceros just to deal with this constant barrage of challenges that Citizen Average simply doesn't face.

And I am anything but impervious to the long-term effects of all of this myself.

Several years ago now I faced the most significant challenge of my life. I wasn't born with a silver spoon in my mouth financially, but in many other ways I was. My parents passed me great genes, and created an early childhood environment that was second to none, full of encouragement and opportunity. My sister is, well, just the most wonderful sibling anyone could hope for. I recognise

in myself many of the attributes I describe above that I believe are so important living with disability. Well, maybe "patience" is not my greatest strength.

As a result, when at age 16 a split second "decision" to take a dive into shallow water at Avoca Beach north of Sydney at the wrong angle resulted in a high-level spinal cord injury and a future whose only certainty was a lifetime of dependence on a wheelchair for mobility and on other people for many other basic aspects of my life, those same attributes became my greatest asset. I immediately started to think through what I would need to do to continue with my plans to finish school and university leading to hopefully interesting and well paid work, a nice place to live, hopefully with a nice girl who'd fall in love with my good qualities and ignore my bad ones. I don't ever recall thoughts of grief or hopelessness, or of any doubt that I'd find a way to deal with this. Perhaps I'm kidding myself - the mind is a funny thing.

On the other hand, that's basically how life has turned out for me. After 10 months in Royal North Shore Hospital Spinal Injuries Unit, I returned to a wonderfully supportive school that did everything possible to help me gain my Higher School Certificate. One of my greatest challenges at the time was getting to and from school, which prior to my accident meant a one hour journey on two separate trains. The Commonwealth Rehabilitation Service came to the rescue and provided door-to-door transport for me for the rest of my schooling and throughout university - an investment in me by the Australian people that I now repay through my taxes every three months.

I bumped my way through university, failing three out of four subjects in my first year, then finally completing what could

only be described as a lacklustre university experience with an Arts degree majoring in economics and psychology. On the upside, I was far more successful in romance, and met and married my first wife while still at university. We were together for 16 years.

Turning my thoughts towards employment as my university days drew to a close, I was drawn to a familiar logo in the employment section of the Herald. The same company that responded to a letter I penned while still in hospital seeking the donation of a typewriter that I would need for my studies, was seeking marketing trainees.

As has been the case many times in my life, good luck kicked in, and my first interview happened to be with an executive who turned out to be one of the world's really great people. He told me years later that I had immediately impressed him and he decided on the spot that he was going to do whatever he needed to do to offer me a job. Which he ultimately did.

I spent the next 28 years with IBM, initially in the technical side of the business, but ultimately in a wide range of marketing, strategic change management and executive roles. I spent a good deal of my life on aircraft, almost continually travelling the world. I finally left IBM eight years ago and now run my own consulting business focusing mostly on social change.

Not only am I not going to deny that I've led a very nice life, I'm proud of it. I'm also very aware that, take my disability out of the equation, and my life is anything but unique. Business people spending large chunks of their lives in airline lounges are dime a dozen.

Ah, but I digress. I started this meandering journey through my past by

referring to the greatest challenge I have faced in my life. No, it was not the onset of my disability. Nor was it the divorce from my first wife, although that was undoubtedly more challenging emotionally than my disability.

It took years to recognise it, and even then it was only due to the concern of the person who saw me every day – my personal assistant – that I did so at all, but 25 years after my accident I faced a period of severe depression. I must have hidden it well, even from myself, partly I suspect because it didn't seem to be affecting my work. It didn't help that I had never faced depression before, and I didn't recognise the signs.

Looking back, though, the signs were obvious. I'd be sitting at my desk and just burst into tears. "Pull yourself together, Mark – what have you got to cry about?" I'd berate myself.

And the rational side of me was right. I had a great job, I was travelling the world, I was living in a beautiful home, I was well off financially, I was surrounded by beautiful people. Nothing to complain about, surely?

On one level that is all very true. But something was terribly wrong.

I am compelled to digress once again. As a result of this experience I have developed a theory that helped me more than anything else to explain what I believe was going on for me at the time, and helped me understand what I needed to do to get back on track.

I believe that, on the day we are born, every one of us is taken to the Bunnings of Life to pick up our Life Toolkit. Just like the real Bunnings, the Life Toolkit section contains a vast array of toolkits, some large, some small, some with premium quality tools, others with a more basic

starter set. One of them has our name on it.

The Toolkit itself, be it the large and robust one proudly showing off its fine form, or the small canvas bag that may be more agile but a little short on space to add more tools later on, is our DNA. It's what we are born with. It's our personality, our motivation, our intelligence. And the starter tools that every Toolkit contains are the environment into which we are born. Our parents and our families make up the majority of our starter tools, complemented by the broader community and society around us.

We pick up our Life Toolkit and we carry it with us every day of our lives. It is the most valuable asset we will ever possess.

We constantly do two things with our Life Toolkit. Every day of our lives we pick up new tools. The vast majority of the new tools we gather are the learnings and skills we gain throughout our lives - our life skills. We gather some of these skills through the formal education system - we learn to read and write, we learn about science and history, we learn vocational skills that help us get a job. And we gather many more through the School of Life (a.k.a the School of Hard Knocks). We get into trouble as a kid and we learn how to deal with it. We meet someone new and we learn something new about human nature. We argue with our families and friends and we learn how to express ourselves. And we learn more about ourselves - what we are good at and what we are not, what we like and what we don't.

The second thing we do with our Life Toolkit and the tools it contains is sort out life's problems. We face an obstacle or challenge, we put our Toolkit down, we rummage through its contents to find the

right tool for the job, and we sort the problem out. For the most part we are not conscious that we are doing so, nor that when we struggle to find a solution it's probably because we don't have the right tool for the job. But my observation of people has convinced me that the size and content of our Life Toolkit is the key determinant of our overall quality of life.

I didn't know I was doing so as I lay immobile in the Emergency Unit at Royal North Shore Hospital all those years ago, but I look back now and I realise that I was drawing on every life tool I had in my Life Toolkit to think through how I was going to deal with my disability. I thank my lucky stars every day that I was blessed with a large Life Toolkit and a set of life learning experiences that have filled that Toolkit to the brim with high quality life tools.

What I didn't realise at the time, nor did I realise in the subsequent years leading up to my depression, was that I was actually wearing out my life tools more quickly than I was replacing them. As I sat at my desk sobbing, confused, even frightened, and with virtually no understanding of what was happening, I was actually reaching into my Toolkit to deal with the day-to-day challenges of living with disability as I had done every day since my injury, but there was nothing there.

And there was nothing there because living with a disability is just so damn hard. So unnecessarily hard. I had worn out every tool I had.

Unlike Citizen Average, who might have to delve into his or her Life Toolkit to sort out challenging situations relatively infrequently, I, and other people with disability who strive to lead full and inclusive lives, have to call on our Toolkit all day, every day. That's how I deal with the constant challenge of finding someone

to get me in and out of bed every day. That's how I deal with entering a building through the tradesman's entrance if at all. That's how I deal with being late for meetings because the public transport system is so woefully inaccessible. That's how I deal with travelling in the baggage compartment of the train to Newcastle. That's how I deal with the fact I can't see out of the windows of most "wheelchair accessible" taxis. And that's how I deal with the waiter who talks to my wife and not me, with the shopkeeper who refuses me entry into the store because "there's not enough room for your wheelchair", with the well-meaning person on the street who declares that I'm "such an inspiration". Ordinary man leads ordinary life ... how does that become inspirational?

I emerged from this very dark period over a decade ago and, touch wood, have been okay since. But I didn't do so alone. My wonderful PA - now my beautiful wife, Bev - almost forced me to seek professional help. The fact that she had control of my diary made it inevitable.

As my psychologist came to know me she offered exactly the advice I needed. It was during my third session with her, if I recall, that she uttered words to the effect "Mark, I think you have the capacity and skills to sort this out yourself, but you won't do so until we lift this dark cloud of depression that hangs over you". That convinced me - somewhat reluctantly - to take anti-depression medication for what turned out to be only a short period. Within a week I felt the dark cloud lifting and, as she predicted, my Life Toolkit and the tools it contained started getting me back on the rails. Back on the Life Superhighway with Citizen Average.

I don't see too many other people with disability on the Superhighway of Life. I'm certainly not the only one, but as

education, workforce and other participation statistics from around the world have been confirming since records began, the vast majority of people with disability are travelling on the Backroads of Life, full of potholes, dangerous curves, broken bridges. And they are doing so, not in the fast, safe and reliable vehicle used by Citizen Average, but in a horse and cart. Without a horse.

"Segregation Road". That's the name of the goat track most people with disability are forced to travel on. The towns through which it travels are as segregated as the road itself. Sheltered workshops (now rebranded "Australian Disability Enterprises"). Segregated employment. "Special schools". Segregated education. "Respite care". Segregated holidays. "Group homes". Segregated living.

I can hear my name being furiously scratched off Christmas card lists as I write. Many people don't like the way I describe these things, and many don't agree with my interpretation.

Many decent, caring people, including many with significant lived experience of disability, argue that, while they genuinely - almost desperately - would like to believe that a person with disability can go on a holiday with everyone else, can live in a place of their own choosing with whomever they choose to live, can be just like everyone else, the harsh reality of disability is that this is just impossible. The pain that accompanies their words is almost palpable. Broken dreams and broken hearts.

But it is NOT impossible. There are people with every type of disability at every level of severity all around Australia and the world who are working in open employment at award wages, who are receiving their education in mainstream schools and universities, who are taking

their holidays on cruise ships and caravan parks, who are living in ordinary houses and apartments in cities and towns across the country. Nowhere near enough, mind you, and they have to work incredibly hard to make it happen, but they do exist. They are living proof that there is a better way.

There is another group of people who also don't like the way I describe these things, but unlike the first group, I have little time for their views. They are the people who do very nicely thank you very much out of the status quo. They are threatened by the thought that a person with disability may decide to take his or her life into his or her hands. After all, that might mean that the person with disability might not need them anymore. Or that the person with disability might still need support, but will no longer be just told what support he or she needs. The person with disability might just become a demanding customer, heaven forbid. Hopefully the National Disability Insurance Scheme, with its market-driven, "user choice and control" principles, will weed a lot of this out. Time will tell.

Lest my words encourage a conclusion that I'm some sort of rabid pinko leftie who smoked too many funny cigarettes at hippy music festivals in the halcyon flower power days of the 1960s, consider this: the UN Convention on the Rights of Persons with Disability, to which Australia was an early signatory, in *Article 9 – Accessibility*, declares that:

"To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems,

and to other facilities and services open or provided to the public, both in urban and in rural areas."

On living independently, it calls on signatory States to ensure that:

"Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community"

It makes similar calls on employment, access to the law, education, recreation – on every aspect of life and community. I think I'm in good company.

Just to set the record straight, I was too young for Woodstock or Glastonbury. Damn.

Australia is at a crossroads in relation to the inclusion of people with disability. The National Disability Insurance Scheme is the most significant and potentially the most positive disability reform the world has ever seen. It could create the right conditions to close the participation gap once and for all.

But the NDIS can't do this on its own. Turning again to the Life Superhighway analogy, there are two things that must happen if people with disability are to stop travelling on the back roads and start travelling on the superhighway. The NDIS does only one of those two things.

If we were to take a virtual helicopter ride over Australian society today we'd see a very similar picture to the one we would see if we took a real helicopter ride over the old and new Hume Highway. We would see the majority of people

travelling at speed in comfort on the new Superhighway. And we would also see people with disability – and many other disadvantaged citizens – travelling much more slowly and much less comfortably on the old highway.

Some of those people with disability will be only just leaving Sydney – they have only recently been born with or acquired a disability. Some have made it to the outer suburbs (it's an old suburb called Institutionalised Housing – it's slated for demolition and a major rebuild, but some of the residents are holding firm), some are passing through Goulburn (a.k.a. Special School – it's starting to look like a ghost town), others are over the border but are having trouble finding their way to Further Education (midway between Albury and Melbourne) – it's marked on the map but there's nothing there. Still others have made it to Melbourne's outskirts to the poor but working-class suburb of Sheltered Workshop.

Few – very few – have made it to Melbourne itself. They look tired, battered and bruised. But they have made it, and they are partying like there is no tomorrow. Not a bad plan. Who knows how long our current focus on disability reform will last?

The first thing we need to do, then, is to build on-ramps along the full distance of the two highways, providing opportunities for people with disability at any stage of their life journey to join the superhighway with everyone else. Those on-ramps are accessible websites for people who are blind, accessible public transport for people with mobility impairment, live captioning on every broadcast and closed captions on every form of visual media for people who are deaf, every written document available in simple English for people with intellectual disability, and an encouraging and

welcoming demeanour from Citizen Average who has shed his or her long held low expectations of the capacity of people with disability.

The second thing we need to do is to replace the horse and cart that a person with disability is currently travelling in with a fit for purpose, safe, comfortable and fast vehicle that will allow the person to join the fast flowing traffic at the end of the on-ramp.

That vehicle is our disability support system. For me it is a carer to help me in and out of bed each day, a power wheelchair so I can move around, voice recognition software so I can write, and a few other bits and pieces. The exact nature, type and amount of support I require will not necessarily be the same as the next person with disability, even if that person has the same type of disability as me – his or her life won't necessarily be the same as mine, after all, so why would she or he need exactly the same support but I do?

Paying for that vehicle, and building a market to ensure that the vehicle is available for purchase in the first place, is the role of the NDIS. While it is still early days and the full rollout of the NDIS has only just begun, its potential to prepare people with disability with the support they need to join the superhighway with everyone else is profound.

Well done Australia for supporting the NDIS. If the NDIS achieves the participatory outcomes predicted by the Productivity Commission, which will see the \$22 billion cost of the NDIS more than paid for through the increased economic contributions of the people with disability it supports, not only will people with disability be lifted out of abject poverty where many currently reside, not only will Australia redeem itself as a pariah in

the Western world in terms of its embrace of people with disability, but everyone in our nation will be better off.

But what about the on-ramps? Who is responsible for them?

You are.

Do you run or have influence in a company? Is your website fully accessible? If not, fix it. Can people with disability get to your office or showroom? If not, fix it. If a person with disability shows up for a job interview, qualifications in hand, do they genuinely – GENUINELY – get a fair go? Do you look at that person and recognise that the highly refined decision-making and problem-solving skills, and the determination that person possesses that has brought him or her to your office in the first place are exactly the skills you need in your business? If not, fix it. Can a person with disability use every product or service you deliver, can they use your hardware and software if you are in IT, can they travel in comfort, safety and dignity if you run an airline (JetStar, Virgin and Tiger in particular – are you listening?), can they go to the opera or ballet and see what’s happening on the stage (Sydney Opera House – are you listening?)? If not, fix it. If you run a shop or restaurant, do you welcome people with disability with open arms? If not, fix it.

Are you on the professional side of the disability equation, running or working in a disability support organisation or in government? Do you genuinely – GENUINELY – believe that a person with disability is as capable as anybody else and that your role is not to “look after” the person but to transfer your knowledge and skills so they can look after themselves? If not, fix it or get out of the way. Do you see that your ultimate objective is to become irrelevant in the

lives of people with disability because you’ve been so good at what you do that they no longer need you? If not, fix it or get out of the way. Do you think that your own job could be done just as well by a person with disability as it is by you? If not, fix it or get out of the way.

If on the other hand you are one of the many wonderful, hardworking, clever, aspirational people who work in the sector, offering to many people with disability a beacon of light and hope, thank you for all you do, and rest assured your continuing support is very, very welcome. More power to your arm.

And if you are neither of these two things, if you are just Citizen Average, is there anything you can and should do?

There sure is. Start by just listening. Listen to people with disability telling their own stories. Try to the best of your ability to understand how you might feel in that stinking railway carriage on a trip to Newcastle. If that makes you angry, pick up the phone to your local politician and demand that the problem be fixed or he or she won’t get your vote.

There are only two resources at our disposal that we can use to create and run the society and environment in which we live – the finite raw materials of our beautiful planet, and the infinite resource of the human mind and spirit. Many would argue we have been overusing the former since the Industrial Revolution, and underutilising the latter.

People with disability would certainly agree. And they are ready, willing and able to do their bit to make this a better world for everyone. Are you with us?

ABOUT THE AUTHOR



Mark Bagshaw is the Managing Director of the innov8 Consulting Group, and a lifelong advocate for social reform. He worked for 28 years in IBM in a range of senior management positions, and has particular skills in strategic change management.

Mark has also undertaken many national and international leadership roles in the social development area. His current roles include Co-founder and Chair of The Able Movement and Deputy President of the Australian Council of Social Service (ACOSS). He has used a wheelchair for mobility since the age of 16 when a spinal cord injury caused through a diving accident resulted in quadriplegia.
