

# **Pathways 6 Conference 2002**

## **Our Opiate of Choice**

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### **ABSTRACT:**

This paper is a personal account of the way in which physical disabilities did not preclude the speaker from an integrated education. We follow his journey from primary school through to his completing his Bachelor degrees at University. As the speaker reflects on the way in which an inclusive education allowed him to participate in society we are presented with a clear insight as to how we must strive to continue creating such pathways. The speaker not only presents a thesis as to the way in which an education has benefited him, but delivers an argument as to the way in which integration benefits the wider community as well. The subtle challenges that people with disabilities have are represented as being an extension to the greater challenge of meeting a desire to live as an independent member of society.

### **1. KEYNOTE ADDRESS:**

Last year I travelled overseas for some six weeks. Due to a combination of good fortune, generous friends, optimism and pure luck I had a fantastic sojourn that took me to San Francisco, Vancouver, Calgary, Jasper, Barcelona, Seville, Madrid and London.

When I was in Calgary, a city at the foot of the Canadian Rockies, I attended a folk festival. It was held on Princess Island. I went with my mate for two perfectly warm Canadian Summer's days. The Sun poured down on us and the carnival like atmosphere was intoxicating. There were folks on rugs and deck chairs drinking, eating and laughing. The sound of international artists burst about us, from African drummers, to Celtic pipers and of course our very own wonderful Australian accent cut through the North American air with a precision that made me smile when The Stiff Gins, performed on stage.

Pretty much on arrival at the venue on the first day we found a perfect position under a large, shady tree. I could see the stage without blocking anyone else's view. Having arrived in the morning the day wore on, and the acts came and went and the music and the mood built within us a sense of place as we paused in our journey across the world.

During the closing stages of the concert on this first evening my attention was partly drawn to a father and a son who sat not so far from me.

The father was a big, strong boned man. He was probably forty years of age. And his son was cut from the same rock. They shared the same jaw line, the same dark hair and it was obvious the boy would grow into the strong, tall size of his father.

But whereby the father could sing, and he could move, and clap and dance and sit and stand and stretch easily his son could not. His son was living with cerebral palsy and was affected by it quite markedly. He was unable to speak freely, his strangled words were difficult to comprehend, and the spasticity of his movements were awkward and tiring.

On the stage at the time was David Byrne. Some of you might know him, he was the former lead singer of Talking Heads, a popular band from the 1980's for which he would wear an over sized suit and dance in a style that was his own.

This particular night of which I speak he sang the most wonderful mixture of Talking Heads songs, and those of his now very successful solo career. He sang in a voice that was melodious and clear and his fantastic band moved with a groove and we who were there allowed the Canadian summer to settle around us as the Moon raised herself up into the star bright night.

Byrne's voice sang out the lyrics:

*"Well we know where we're going*

*But we don't know where we've been.*

*And we know what we're knowing*

*But we can't say what we have seen."*

I noticed then that the father had lifted his son from his wheelchair, and he held him tightly beneath the arms from behind him so that they could both see the stage. And then this father and son danced, in a fashion. The great man and the greater boy rocked.

As the night sky closed in around us and the lights illuminated the stage, Byrne's guitar reflected the bright flashes of the crowd's appreciation and the young man and his Dad were joined.

The music Byrne played became the instant sound track for a simple performance that captured a mood of joy.

Together these two, the man and boy, bellowed with Byrne the words:

*"And we are not little children*

*And we know what we want*

*And the future is certain*

*Give us time to work it out."*

And I saw them, this father and son, as you would see them, with eyes that know too well part of the story it was that they had to tell.

I knew in the moment of their joined dance, as their voices sang out with the rest of the crowd, as they clapped and moved with awkward and yet assured timing with the music, that they were celebrating Life.

The father and son, together and apart, as one and divided, were summing up in the moment forever captured in my mind the declaration that despite it all they were alive. No matter what pain the past held. No matter what the future could not promise. Let it be known the hard living was now easy and as easy as it could ever be.

This father and son represent in part the way in which so many of us who have disabilities, live our lives: Moments of extraordinary enlightenment can fall upon us in ordinary circumstances. It is like a photograph that captures an image of a time and place that is difficult to appreciate unless one has lived what could be said to be a Life that is not ordinary.

People with disabilities have an ordinariness that is defined by obstacles and impositions, of a physical, spiritual and emotional nature, which have been overcome. However, we do not often have the opportunity to draw breath and sit quietly to reflect on how far it is we have come. That is why a conference such as this is so important. When people with disabilities live their lives most do not tend to dwell on the difficult things which cause us our trouble. The fact that we cannot see and require the use of a guide dog or are frustrated by the lack of tactile markings in the cityscape are matters of fact that are absorbed with the daily events of living.

We are a diverse people and belong to a sometimes fractured tribe, but for the better part we respond most assuredly when the drum that is beaten is done with a rhythm to inspire us to move forward rather than to remain standing still. Nothing is gained from yearning for impossibilities and allowing for bitterness to taint our hearts. Optimism remains the opiate of our choice. It is that which allows us to explore the options and potential of tomorrow. So we make do with what tactile markings are available, we agitate for improvements, and we enjoy the sunshine that falls on our face and the breath of the summer breeze when she carries the scent of the wattle in our direction. We get on with the living despite that which can make the living difficult. And like the boy with his father, we accept those moments when things make simple happy sense without hesitation.

None of us are the same, of course, and our experiences are unique. My disabilities effect me very differently to the way in which the Canadian boy is effected by his. The fact that I can see and hear means my experience through life will be much more different to that of an agile and robust deaf person. Nevertheless there are common experiences that unite us and which unite people who have found a vocation in various areas of disability, all of which are represented in some manner or form in this conference.

The common experiences we share are those which draw us here today: The pathways that we seek and forge together and apart into society. We share the common understanding and experience how our disability effects us in social and cultural and practical ways. Education, employment and access to cultural activities and advancements in technology are all issues of particular concern to we people with disabilities. The manner in which we deal with these differences and strive to ensure that the inequalities they create become less important is our story to share with each other.

I was born at the King George Hospital, in Camperdown on the morning of September 11 1970. I was delivered via Caesarean.

I was the first child born to my folks. I was the first grandchild on both my paternal and maternal side. Apart from these things, which are of themselves nothing extraordinary outside that of the immediate experience of the family, my birth was thought to be a matter of fact that would involve all the typical emotions of joy and delight invested in something with limitless potential. But when I was held in the gentle hands of the obstetrician I struggled to draw my first sharp breaths. It was obvious that all was not as it should be. At first they were unsure as to the diagnosis, however, my breathing difficulties gave the doctors enough cause to tell my parents the sad prognosis that I did not have long to live.

Despite this fact, as the oxygen found its way into my lungs, Mum and Dad, remained determined to see tomorrow arrive with the expectation that another tomorrow would follow it with potential. They poured love into my soul. And the week that was thought to be my first and last was followed by another, which was steadily added to by yet another seven days. And here I remain.

I was diagnosed by my maternal grandfather, an obstetrician and gynaecologist, as having Diastrophic dysplasia.

There is a one in a million chance that one can be born with diastrophic dysplasia. Both parents have to carry the recessive gene. So fortunately I will not have children with the same problems unless my partner also carries the gene.

The basic facts that represent people with diastrophic dysplasia are these:

Obviously one has shortened limbs. I am a little bloke. Always have been and no matter how many Vita Brits I might eat there is no way that is going to change. But as a woman once whispered to me “It ain’t the size of the dog in the fight that matters but the size of the fight in the dog.”

We also have a spine that tends to not grow in the good, straight strong fashion, as it should. Instead it develops a curvature, and in my case, it did so dramatically. It twisted and turned very quickly so that by the time I was ten years of age I required an operation to try and stop this happening. The spinal operation I underwent in 1980 certainly stopped the spine deteriorating any further, but unfortunately as a result of the damage done to the spinal chord I ended up a paraplegic. So from the age of ten I received my first set of wheels, as it were, and I was on my way.

There are other things that diastrophic dysplasia involves. Strange quirky physical attributes. For example some of the knuckles in the hands are fused so that I cannot make a fist. This proves frustrating at times as I find it impossible to get the top off a cold bottle of VB when the thirst is upon me.

There is also the tendency for a calcification of the external ear, or in other words, for one to develop cauliflower ears. I have two!

As the majority of you would know cauliflower ears are the trademarks of boxers and rugby forwards. They are the reminders of battles won and lost in moments past. And realising this at a tender age I always felt somewhat privileged to be counted as being among the harder men of society. There were pugilists, prop forwards and me.

But of course on the day that I was born the high emotion of the moment of my arrival was surpassed by the heavy realisation that things were no longer the same.

One of the most remarkable kitchen table conversations I have ever been involved in occurred when I was 17 years of age.

My paternal grandparents were staying with us in Coffs Harbour.

Mum and Dad were away.

My Gran and Pa, as I refer to them, and myself were just talking about life and the way things turn out one evening after dinner. It was during this conversation that my Gran said she had a

confession to make. She told me, as difficult as she personally found it to share, that shortly after I was born she had taken herself off to Church and lit a candle and prayed that I would not have to suffer long and that I would be taken off to heaven.

Gran told me how she then told my Dad, her son, what she had done. It was not that she did not want me to survive, she explained, she simply felt it was the best thing to do, as it seemed to her that my plight was hopeless. After all the doctors gave me little more than a week to survive and she had never known anything so difficult.

Gran told me that Dad said to her, gently, but firmly, Mum we have a son. And we are going to raise him to be a man. And that is that.

The beautiful aspect to this conversation, and my Gran having the courage to share it with me, is twofold.

It offered me a first hand account of the confusion and shifting shadows that existed at the time of my birth. Thus allowing me a direct representation of the angst that had swept up the family, which I knew had been there, of course, but had never heard mentioned. So that now I was able to appreciate the wonderful human vulnerability's of the moment. And it reinforced with complete clarity the determination and optimism buoyed by love alone that had quickly settled upon Mum and Dad as to what lay ahead for me.

With that story I came to understand from whence I had gained my uncanny ability to comprehend the challenges that I face with frank honesty and the equally determined ability to dictate the terms by which I meet those challenges.

Although I had no control over the direction I took in my infancy those who were my custodians, my Mum and Dad, and my grandparents, certainly did. Within a short space of time the moment of despair that could have left them direction-less came to pass. They were galvanised by a determination to see things right.

These mixed emotions and time of muffled crisis are not unique to me. This is the experience of most people who have a disability. Whether one has an inherited disability, or something acquired, more often than not the initial prognosis has an immediate and definable effect on the individual and those around us. And I think it is important to understand its effect as being a very real part of the human experience we share. The loss of hope and the quest for dignity following it are the stuff of folklore, but for people with disabilities it can be the crucial reckoning of that which we can expect from ourselves and from those around us. They are not things that are necessarily easy to resolve, and it can take time, but it is the on going test that we inevitably have to meet, even if it is not clearly recognised as such.

Obviously in my case there has been a long journey of the Self since the time of my birth and now.

And it has been a journey that has resulted in a posting of firsts.

I was the first child with a profound physical disability to attend my primary school in Coffs Harbour. It was a Catholic Primary School named St Augustine's.

I was the first student in a wheelchair to attend the High School, John Paul College, where I was enrolled from years 7 to 10 in Coffs Harbour.

I was the first student in a wheelchair to attend Coffs Harbour High School, where I was enrolled for years eleven and twelve. It was a school for which I was elected Vice Captain.

I was, during this period, the first person in a wheelchair to compete in the local eistfford competitions.

I was the first on campus resident at the University of Sydney to be in a wheelchair.

As far as I am led to believe I was the first person in a wheelchair to be elected Secretary and later President of a residential college on a university campus in New South Wales, if not Australia.

I was the first person in a wheelchair to be employed as a lawyer by the NSW Office of Director of Public Prosecutions. And I am almost certainly the first if not only member of a recognised sporting football judiciary who is in a wheelchair, as I serve on the NSW Rugby Union Judiciary.

But none of these cited firsts say anything exceptional about me. After all my friends without disabilities have been doing the same sort of things, seeking out experiences of interest and pursuing a future that was to their liking and which befitted their nature. My friends are a high achieving bunch and that which I do pales into insignificance compared to what they have done and do. The fact that these things I have listed were firsts says something about our society and the pathways that did not exist previously.

The mainstream education I enjoyed was, in many respects, an innovation where today it is an expectation. My participation in the community borne of a natural instinct, rather than making me worthy of a distinction.

At St Augustine's, my teachers of the 1970's did not have special training as to how to deal with children with disabilities. They simply met my special needs as they arose, head on. They hardly ever balked at the challenges and I was able to enjoy everything my friends did. In other words, I was damned lucky.

There was one particular teacher who had quite an impact on me, his name is Pat McLaughlin. He taught me in year 3 and year 5. I was still walking in Year 3, albeit with aide of callipers and a walking frame. These callipers were ankle to thigh in length and rather heavy. I had a strange relationship with them. I did not like wearing them, but at least when I had them I could stand and walk, granted it was awkward and uncomfortable, but it was walking. When they were removed I could only scurry about on my knees but it was a lot more comfortable, despite the removal of my ability to stand.

Pat used to take our class on Thursday afternoon's down to the sports field for a bit of a break at around 2 o'clock. One of the games he used to get us to play was "Bomber". The class would be divided into two teams and sent out onto a portion of the field which would have an imaginary dividing line. The purpose of the game was for each team to keep the inflated ball that was thrown into the field of play in the air. If the ball happened to be missed by a player that player would be dragged from the field. And the ball would be bounced from one team to the next until such time as there was only one player left and he or she would be declared the winner.

Quite obviously I was unable to play this game as the kids ran about nimbly and jumped for the ball with various degrees of dexterity. Instead I would watch and call out advice and laugh on the sideline up until there was say 10 minutes left in the sports break. Then, having

removed my callipers for me, so that I was on my knees and ready for action, Pat would blow his whistle, and then invoking my Nickname call out "Laffo Bomber." Then all the kids would enter the playing field and drop to their knees and we would play the entirety of the game on our knees.

It was the first level playing field in the country.

It was because of my parents that I attended this school. It was their decision that I should have a typical coeducation. It did not occur to me until I was a young adult as to how different things could have been.

I can recall very clearly heading to the Coffs Harbour Council pool with my year two class one day when we came across the kids from Yallberlinga School. Yallberlinga was the *special school*, as it was then known. The students had a mixture of disabilities. Some had physical disabilities, others were intellectually challenged, or they had a combination of both. I guess the majority of the students were older than my classmates and I who were around six years of age.

I remember how we stared at them with our mouths gaped open, empty of malice but full of curiosity, as they filed past us with their teachers. My inability to identify with these other kids was something that stayed with me for many years. For a long time I would try and avoid contact with people who did have disabilities for fear of being regarded as someone who faced limitations: An irony which has not been lost on me since. It was of course an immaturity that one expects in a kid, but which left a mark on me for a long time.

My transition from primary school to high school for years 7 to 10 was an easy one. John Paul College was opened the year I arrived and it was the first fully accessible school in the area. When I left that school to attend Coffs Harbour High for years eleven and twelve in 1987 there were some major difficulties as it was full of stairs and the department of education refused to fund any changes required for me to enrol there, despite my desire to do so. If it were not for the efforts of a couple of teachers and members of the local rugby club who gave up time to build the ramps themselves I would never have been there.

But of course away from these bricks and mortar issues, and indeed apart from the books themselves, the largest challenges I faced at school occurred as I got older and the young boy that was me grew into an adolescent. All those changes and challenges we face socially around that period became my own and I was among boys and girls who were growing into young men and women when they did.

It was the time of awkward truths.

The little known worries of the boy, despite the difficulties I had did not consciously disturb my hazy days. But when adolescence arrived the last vestiges of my pyjamad innocence was lost and replaced by a realisation that Life contained bigger things of consequence. I became aware, as we all do, of those things which stand outside us, and of that which breathes inside us, and of the forces at play that go to create what we will be.

I became aware that we are very much responsible for the direction it is we take in Life and what we will make of opportunities won and lost.

It was the time when I became aware of the way in which my disabilities separated me physically from my peers. Where before it had simply meant that I could not climb trees

where the others could, or that my ability to play handball at lunchtime was not as skilled as the others, the real challenges ahead of me had been hidden up until that point in time.

My mates started to grow taller and stronger although I did not.

My Pals began to go for their "L"earners permit, which for me was impossible. The independence of travel was obvious, even if it was in their parents' car. And although I was and remained a popular kid the dynamics of the social order was changing around me.

When we attended the Blue Light Discos the fundamentals as to what young people find and discover in the semi dark were not necessarily mine to find at that time. As the eyes of boys and girls began to focus on the differences between the sexes as something of interest I began to see how my situation was marked with a significantly different brush.

These are of course common themes shared and appreciated by all of us. It is the chemistry of life. The experience of adolescent longings were not unique to me. They are at the heart of the teen flick, the kid who wants to kiss, or better still to be kissed. But it was a solitary journey made all the more intense because of my physical disabilities.

I was, put simply, a young man who was beginning to find his way and his place in the world without any real plan or method by which to do it. And for all the love of family and friends I had it was a matter of figuring it out on my own. It was a matter of sizing up my challenges and dictating the terms by which I would deal with them. It came to a situation of having to judge my self worth.

Interestingly one of the great influences that assisted me at this time was sport. And the sport that provided me with a rhyme and a reason was Rugby Union.

Obviously I have never taken to the Rugby paddock, but the game is in my blood. My old man has coached Rugby all my 32 years and thus it has been with me forever. And with it have come experiences and friendships and lessons learned that have assisted to shape me into the evolving man I am.

Rugby was an important influence on the developing, formative years of my youth. And I can clearly recall the autumn day in 1986 that it took on a special moment of significance.

At the time I was working after school at a law firm. The firm was called *Watts and McKinnon* in Coffs Harbour and it was owned by a dynamic wife and husband. They were relatively fresh graduates who had a fabulous flair for the law and an energy and generosity that allowed me a marvellous opportunity to have my first taste of paid employment.

I was just about to enter the front door of Watts and McKinnon for my afternoon's work when I saw Graham Crouch. Graham was the secretary of the Coffs Harbour Rugby Club. He asked me if I would be interested in writing the pre and post match Rugby articles for the local newspaper on behalf of the Club.

It was one of those seemingly benign moments that one can have, which turned out to be significant. Little did I know that in agreeing to do it I was on my way of becoming a member of a sporting team and by that very fact able learn the great lessons that sport has to teach us, especially when we are young.

My role as local Rugby scribe involved me finding out the team lists on the Thursday night after training and then writing an article on the aspirations of the locals for the impending



match. The post match report involved an article describing the events of the day on the paddock and how the various grades did against our opponents.

It was a wonderful experience for a young man finding his way and direction. It gave me the opportunity to develop a craft with the written word as I learned how to tussle with the sports editor and it gave me an insight into my abilities.

As I exerted my muscle on the journalist's pad I was able to earn the respect of my peers and superiors through the written word. I trained and played with every grade from Colts through to First Grade, and I was involved heavily in the Club's way of life. I travelled on the bus trips to Lismore, Byron Bay, Ballina and Grafton and partook in the illicit beers and sang the songs and was very much a member of the team.

As I wrote these articles from 1986 to 1988 I was finding my voice, and well beyond the area of Rugby. The confidence that I gained from being involved in this way allowed me to push my experiences and opportunities in other areas as well. I entered public speaking competitions, and the local eisteddfods even though the halls in which I competed had no wheelchair access and stairs leading to the stage. I wrote short stories and poetry for competitions throughout the State and whether I won or lost it did not matter, it was about finding my talents. I was endeavouring to find what it was that I was good at and to be brave enough to expose myself publicly.

It is no small coincidence that it was around this time that Australian Rugby was on the rise and rise. The Wallabies had returned in 1984 from their UK Tour undefeated, having been the first team to enjoy a Grand Slam victory against England, Ireland, Scotland and Wales. In 1986 they belted the All Blacks for an all too rare Bledisloe Cup series win in the mud and slush of New Zealand. And the names of Steve Cutler, David Campese, Simon Poidevin and Nick Farr-Jones were recognised on the world wide Rugby stage as being the names of some of the best players to not only wear the green and gold, but to strap on a Rugby boot.

Because of Dad's involvement in the game the likes of Cutler, Poidevin and Farr-Jones strolled into my life with all the presence that greatness brings. At first the initial meetings were those you would expect from a fellow meeting his heroes. After all the similarities between them and I was hard to see at first. But as I watched them play the game at an elite level, and uncompromisingly so, I began to see something that triggered a sense of respect deep within me.

So as I wrote my articles for the Coffs Harbour Club, and tested my skills and abilities in other ways, and watched these men of Rugby, the me that is here today began to emerge. I realised that the vulnerability's that I could not escape, were things that I simply had to surpass.

And over a short space of time whenever I came to Sydney to watch Test Rugby these boyhood heroes held out their hand in genuine ways that marked for me a special time of place. And when things got tough and I got crook, or found myself overwhelmed by the greatness of difficulties, they contacted me as if by magic. A postcard would be sent to me as they toured the world, or a telephone call would be made to my hospital bed, and the results were extra special. It was as if the success they managed to create on the football paddocks were mine also. And the losses they suffered were as equally mine.

And then as it happened these boyhood heroes became friends. A maturity of relations took place as the consequences of my growing into a man and our getting to know each other

allowed for the things which we had in common to become strong ties. They had shown me, without knowing it, that if I applied my talents and skills in a way that emulated them that I too would find success away from the football field. The shared victories we had became extra special. They delighted as much in my achievements as I did theirs.

My school life, therefore, was interesting and varied. I had plenty of friends, I involved myself in cultural events, I had my sporting association and I just lived a typical life of a kid growing up on the Far North Coast. I did not take to the waves on a board like some of my friends, but nor did I sit at home wondering why me. And the key to it was I had enjoyed a mainstream education. It was that which provided me with the opportunity to study hard and to feel as if I was always a part of society. It was that experience which confirmed and affirmed my rights as an individual. I had no limitations, as far as I could see, and I felt as if I could turn my hand at anything that took my fancy. I knew what was happening in social groups and what it was like to ask a girl out, and to go to the pub, and to lead the charge to a party and to win an argument and lose a fight. I had been chided and mocked by friends. I had made them proud and I had succeeded and lost and achieved and drifted and found a direction. I had been schooled scholastically and socially so that when I finished my Higher School Certificate at the end of 1988 I was like many other 18 year olds, bursting with energy and ready to go somewhere. In 1988 I was awarded Young Australian of the Year for Coffs Harbour which I regarded as being very special. It was not lost on the locals that I had to be carried onto the stage to receive the award.

Thus when it came time for me to leave Coffs Harbour and attend University I had the determination to do so, and the optimism and fearlessness of youth not to see any obstacle in my way.

I was enrolled to enter St John's College, a residential College on the campus of the University of Sydney. I can remember how excited I was, it was, after all, the first time that I was officially moving out of home at the age of 18. The fact that the building itself was established in 1858 and largely inaccessible did not matter much at all to me. The fact was my bedroom was accessible, and I was able to enter the Dining Hall via the dumb-waiter. Everything else would work itself out, I was sure.

On the flight from Coffs Harbour to Sydney on the day I was to begin living at St John's the aforementioned fearlessness of youth was given a slight reality check. I said to Mum, "You know Mum tonight I am going to have to ask someone I have never met before to help me into bed." Mum, God bless her, kept a composed expression and said, "Yes you will."

And that was it.

And sure enough on that first night at John's, it being the first day of orientation week, which consisted of mild fresherisation and not so mild intoxication, a couple of the lads threw me into bed that night come the end of the festivities. And so it was for the rest of my time at St John's that I was able to rely on my peers to ensure that I could live my dependent independent life away from home.

This speaks highly of the fellows I came across and who are essentially my best friends. These blokes were not fiscally compensated for this and nor did they have any idea that they would be asked to help in such a way. They were economic students, medical students, dentist, engineering and law students who just happened to be my pals. And one of the things about being my pal was giving me a hand, such as ensuring that come the end of the day Laffo was lifted into bed and his jeans and shoes were off and he was right for sleep.

The University itself had a person designated responsible to help students with disabilities. Her name was Elizabeth Egan. Elizabeth was an absolute guardian angel for me: A woman who allowed me the opportunity to experience university by ensuring that the ramps were built, and the doors were opened and the time tables structured in such a way that I was able to meet the demands of university study. Elizabeth was typically one of those special people who regard their profession that facilitates and promotes opportunities for students with disabilities very seriously and with great gusto.

My University experience was without doubt the period at which stage the cornerstone of my future was firmly put in place. It was that time in my life that the gravity of events that would either make or break me came to be understood. For those of us who have pretty striking physical disabilities the fragility of the line that separates us from our totally dependent and independent lives is always understood. I have no doubt that if it were not for my experience of living on campus and falling in with my mates from St John's my life today would be very different, and not nearly as rich as it is.

My college experience gave me the opportunity to enjoy living away from home. It was a time of enormous fun. Our social occasions were always great events. The annual highlights were our St Patrick's Day and Formal Balls. Both were black-tie shows which started off with much ceremony and ended up with me lifted out of my chair being bounced around a jumping castle in the pouring rain with my date and my mates, or singing songs and smoking cigars on the hill overlooking the oval.

My college experience allowed me to find my own guise in the way in which people living independently can as they establish their own networks and social connections. It allowed me to build upon the confidence I had garnered through my school years so that I continued to believe that come the hour I would arrive at the destination that was best suited to me.

Come the end of my combined six years at University and the College of Law I graduated with my Bachelor of Arts and Bachelor of Laws degrees and was admitted to practise law by the Supreme Court of NSW. I was the product, as it were, of an inclusive education. From primary school right through to university I had shared my time with people my own age and the fact that I had disabilities was in the greater scheme of things of no consequence. The pathways that had been created consciously and subconsciously had allowed me to enjoy all the thrills and spills I had wanted too, and to have the undaunted attitude that I had a right to enjoy opportunities of participation like anyone else. But of equal importance, my peers were as strongly inclined to demand from there on in that the likes of me deserved the opportunity to enjoy access to all the goods and services that they enjoyed.

To my mind an opportunity to enjoy a mainstream education is something that should be offered to every child with a disability.

Living with a disability, however, can feel a bit like a marathon swimmer caught in a 25 metre swimming pool. Just when you think you have reached the end and made the distance, you find that you in fact have a hell-uv-a-lot more to do. So you have to do a tumble turn, push off and swim on.

So it was that come January 1995 I was qualified but unemployed.

When I had been at school I had worked a couple of afternoons a week for a local law firm for some pocket money. And then when I was at University I had a paralegal position with Freehill, Hollingdale and Page Solicitors for a couple of years. Then in my last year of

University I worked as a legal clerk at the NSW DPP, but I had to resign from that position when I started at the College of Law and the NSW DPP were not hiring lawyers once I was fully qualified.

I therefore was caught up in the drowning stream of correspondence that began with those dreaded words, *“Thank you for your application but...”*

Fortunately for me a friend who had been some years ahead of me at St John’s gave me a break. Although he himself was a barrister he shared a business at the time with a college mate of his. It was a mentions practice. We would appear in all the courts in the CBD for simple matters as agents for law firms that were in the suburbs or the country but for whom the trip into town would be uneconomical. In simple terms the mentions practice was a half-way house for four out of work lawyers.

I spent 6 months at this job and it was a great experience. I could be seen in all sorts of weather hurtling from our office in Haymarket down through the twisting lanes of Chinatown heading for any number of courts. I got roused upon by frustrated registrars, argued pleas in mitigation before magistrates and got known, visually at least, around the courts. Eventually, however, a temporary position at the DPP became available and the opportunity was given to me to fill it. Then when permanent positions were advertised I applied and fortunately for me I was eventually given a full time position.

At the same time that I began working that January I also began my flatting experience. I lived with two mates from college. We shared a three-bedroom, two-bathroom apartment in Surry Hills and we enjoyed the thrills and spills of beginning life away from the student environs.

The flat sharing experience is something that I have maintained up until this point in time.

My experiences and the benefits I have had because of them are representative of what can be done and has been done. Society can have a very narrow perception of people with disabilities. We are thought to be either dependant upon social security, and locked away in group-houses with little prospect of contributing to society or we are seen as Paralympic athletes achieving great sporting feats on the international stage. When the truth is the majority of us fall somewhere in between the two.

As we continue on our ways in the individual fashion that suits us best we often have to maintain and improve upon the systems we have in place. Even though I am a man of 32 years of age and I have been working full time for some eight years or so, I am not totally independent. My parents still help out in countless ways although I have not lived under their roof permanently since 1988. It is something with which most people with physical disabilities can identify. When one works the expensive demands of living with a disability can quickly eat into one’s income. There is hardly enough money in the bucket for people who are solely dependent upon the state let alone for those of us who are working full time but would like assistance with paying for expensive equipment essential to our daily lives. And of course for the likes of me someone has to get me out of the bed in the morning and into the shower and then dried and dressed at an hour that allows me to get work. We are dependent on others, such as Home Care, and the structured organisation that meets those essential needs from the start of the day until the close of it. However, this is simply the backdrop against which the main production is played out and I enjoy my friends, and my work and my Rugby and my writing and my involvement.

I am also aware, as you all are, for that is the reason you are here, of the need for those of us who can speak out and be heard to call attention to those who need it. Be it our brothers and sisters with physical and intellectual disabilities who are not being given the opportunities they should be as adults. Or be it the little ones who are born today and whose parents will need to feel the strength of what is possible in their heart. I am lucky because I have a gift to speak and I am a lawyer and have a sense for what natural justice means and how it is a basic right. I do not mind telling the Lord Mayor Frank Sartor in public forums that he has let down people with disabilities by neglect having failed to deliver a real commitment to the needs of people with disabilities either living in or visiting this city. I do not mind telling governments more needs to be done to provide opportunities to the basic fundamentals of goods and services for people with disabilities. After all the Mum and Dad of the child with spina bifida are too busy getting on with parenting and the needs of their daughter to also expend energy on the bureaucracy that refuses to listen.

I am increasingly of the opinion that those of us who are engaged in the heady exchange of ideas should make ourselves heard. Especially when the subject matter is said to involve us, people with disabilities. When the debate is opened up on the issue of the merits or otherwise of embryonic stem cell research versus the use of adult stem cells I want to hear more directly from people with disabilities who have a scientific exposure to the issues at hand. I want to hear the opposing points of view expressed by those of us who can be said to benefit from or be marginalised by scientific advancements.

When I read of the hearing impaired lesbian couple from the United States of America Sharon Duchesneau and Candy McCullough, who have both been deaf since birth, who were deliberately choosing to have a deaf baby I was outraged. I was angry that people with disabilities wanted to engineer a child to be born without being able to experience the gift of hearing. And I was frustrated by the lack of contribution to the debate and conversation from people with disabilities in this country. Again the subject was related to people with disabilities but the scientists and ethicists interviewed did not have a disability.

Rights and responsibilities with regards to people with disabilities are to be shared by society, but we who have an ability to do so, must take on the responsibility, where we can, to engage the community directly in a discussion on such subjects and be unafraid to do so. It is the voice of the unheard that we need to amplify whenever it is we think we can.

If perhaps you doubt whether you still have the strength to keep doing that because it can be all so tiring I would like you to consider this. One day when I was returning from the Supreme Court I was feeling particularly good. I had done really well in court. I had cross-examined effectively in the Bails Court and made my submissions in such a way that I felt I had nailed it tight. So I was wandering back to work feeling as if I owned the town. Sure it was only a small matter in court really nevertheless I felt as if everything was in place. I was ten foot tall and bullet proof come what may.

So I crossed Elizabeth Street, from Hyde Park, and I passed the David Jones store. As I did I caught the sight of my reflection in the large windows. And I saw myself as you see me now. I saw that I was not ten foot tall and bullet proof, but rather a small guy who, when contrasted against the other folks passing me by, seemed less agile and robust. The ease by which the others moved independent of wheels and batteries, and their slender limbs and straight backs were all taken in and observed in one glimpse as they were reflected in the window of that store. And immediately that sense of ability and purpose was lost. My heart, normally buoyant and untroubled, sank as I wondered who it is I thought I was and whether indeed I could be the independent person I imagined myself to be.

If you like I was looking at myself with a distant curiosity as I had looked at that boy and father in Calgary, but in this particular case it was me.

My mind was filled with thoughts that seemed to circle with the slow beat of heavy wings as they drifted on the currents of my mood. As I walked on along the block comparing myself with those around me and considered those things which are my lot, I wondered what it all meant. Being of flesh and blood and filled with a spirit that thrives on companionship, love and intimacy and the need to be touched sometimes all we want to do is to let go and rest easy. Not much more is desired apart from a soft touch and an exchange of messages without words.

I am often haunted by the feeling that tomorrow holds no guarantees. Perhaps this is attributable to the precarious beginning that I had. As a consequence I am a great believer in one making as much of today as possible in order to ensure when tomorrow arrives it has something good to follow it. It often feels to me as if the hours are crowded into moments that sometimes seem too slow, and then too fast. I see there being no room to forgo opportunities to live positively. Having bid farewell to too many friends whom found the living too tough and the dying too easy despite everything they had I treasure each of the moments that Life has to offer. It is to be had and enjoyed and shared. I try to reach out often to those I love to tell them it is so and to see the best things that are available to us in life.

These days we know too well that beauty is not a myth, but a desired commodity and the eye of the beholder seems of less importance. However, nothing can dilute the essential truth that is the potential that we each have to contribute something to our society and to gain something from others. No matter how much we might want to be protected from the steady gaze of reality at times we cannot be. But as always what we lose in innocence we gain in understanding and if we are a clever about it, we can understand more about ourselves and what the value of that which is in or hearts and in the hearts and actions of others.

I thought about these things as I wandered away from that David Jones window and endeavoured to understand what it was that was troubling me. I thought about the initial love Mum and Dad gave me as I have described to you. I thought about the purpose of everything and how what was to come of me essentially rested with me. And as I considered these things I made it to the end of the block and when the lights changed I crossed the road and got to the next block. I thought about the way in which some people make me smile and what it is like to hear a live band and how sweet it feels to be in a foreign city drinking the local beverage and tasting life, when it was time to cross the road again and to get up the curb ramp on the next block. And I continued on in this fashion until such time as I arrived here with you people today, gathered for the purpose of forging pathways and sharing our stories and aspirations and plans. I have arrived here possessing all the strengths and weaknesses that are as obvious as the eye or ear can translate determined and grateful and inspired to continue on to the next block by virtue of the fact that somewhere along the line you people will join me creating places and spaces that will benefit all of us.