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## **David Heffer – a man who matched his words to his actions**

***Allan Mayer is joint winner of the David Brandon Essay Competition – The person who has most inspired me. Allan's entry is about David Heffer. Those who knew David Brandon will recognise many of his feisty character traits in David Heffer.***

Lesley Twyman sat in a café waiting for her friend to come back with their coffees. She had exciting news to impart – so exciting that as her friend returned Lesley turned to two strangers at the next table and said:

"I hope you don't mind, but I am about to tell an amazing story. I know that when you hear what I am saying you will stop what you're doing and listen, so I'd like to invite you to join us so that you don't miss anything."

So Lesley told the story of her son, David Heffer. She told them of a resilient child who had battled acute illness. She told them of a brilliant young nursing student who became a respected and innovative care worker. She told them of his travels and of how recently she had found out that he had turned up as a lead character in a novel which is dedicated to him.

She told them how, when David died, it drew the attention of the national press.

But not for reasons anyone would have wished.

Twenty-five years earlier...

I am ascending the escalator at Euston station. My fiancée is waiting at the top, but she looks quizzical when she sees my scowl.

"That bloody David Heffer".

I had spent a Friday afternoon in my new job as a Residential Social Worker listening to

debates about terminology. I was there to help people and this was not at all what I had expected. Some guy called David had prolonged the meeting by announcing that we were no longer to say that people had 'problem behaviour' (which was at that time a technical term); instead we were to say that they had 'challenging behaviour'. Furthermore, he had initiated a debate about what we would call the residents of the new bungalow. The terms 'users' and 'clients' were rejected because each were felt to have connotations outside the world of care.

This David guy who, although he was in a managerial position, wore a pony tail and earrings, led us to conclude that if the people were to be referred to as a group they should be called 'the people'.

That evening I would sit in my Northern local and rant about the strange ways of trendy southern social workers. And herein lies a warning: when you first meet that person who most inspires you your first reaction may be that they annoy the hell out of you. That is the nature of inspirational people. Sometimes they make you feel uncomfortable.

And another thing: there were a lot of people at the meeting that day. I can no longer remember anything that anyone else said.

As a Senior Residential Social Worker, David played a lead role in assisting people in their move from a long-stay 'Mental Handicap' hospital back into the community from which they had been taken as children. Radical in his beliefs, innovative in his practice and inspirational to all around him, he set the benchmark to which I have worked for over two and a half decades. He was one of those special individuals you are occasionally fortunate enough to come across in your life who are so true to themselves that the tune they dance to gets inside your head and stays there.

Recently I learned that he had not only been a remarkable man but a remarkable child. I knew that David had asthma; what I didn't know was that his asthma had been so bad that he had spent two years of his childhood in a sanatorium. Even as a child he embraced life, not fretting for home as most of us would but enjoying the opportunity for learning.

As David grew up it was clear that he had a mission. He trained as a mental handicap nurse, working in the Victorian institutions that were still thriving in the 1980s. But it wasn't David's way to accept the norms of the institutions – he saw the 'patients' as individuals, as human beings who were not sick but, purely due to some strange quirk of history, had ended up living in hospitals.

David, or 'Heff,' as he was known to his fellow nursing students, trained at Bromham Hospital in Bedford. Even then it was clear he would approach his work with people with learning disabilities in a way led by the desire to connect with people on a real, human level, and not as directed by any text book.

He once got himself into deep trouble as a student nurse. He told me how a patient had asked him for a go on his motor bike. David always cut through the assumptions of the over-protective with a simple 'why not?' He had ridden round the grounds, the man on the back whooping with joy, until a senior member of staff stepped out in front and demanded that he stopped.

That was David. Always willing to take those 'risks' which would give people real life experiences. He understood that we all need those adrenalin-filled moments, regardless of our perceived handicaps.

When I knew David in the mid-eighties he had embraced political correctness in a way that we would now probably consider extreme and was fired up with the concept of normalisation. At times the staff team joked about his radicalism but I think David had seen in normalisation an expression of beliefs he had instinctively always held. People with learning disabilities had the right to experience normal lifestyles. This was a tenet from which David never deviated and, whether through conversation or action, he set out to dismantle any obstacles which stood in its way.

He was a stickler for correct terminology firmly believing that, hand in hand with discrimination, goes negative stereotyping terminology. We did not work with 'The Mentally Handicapped' but with 'People with a mental handicap.' With David it was always 'people first'.

These days we tend not to pay as much attention to these things, but before we take a superior attitude we would do well to remember what a powerful tool language is in the perpetuation of stereotypes. Back then we were confronted with the reality of people with learning disabilities being treated as sub-human, sleeping in hospital wards, living to monotonous routines and being denied the 'normal' luxuries the rest of us took for granted. And this view was reflected in and perpetuated by the language we used. They were 'the mentally handicapped,' subnormal, low grade, objects of fear, recipients of charity or the targets of cruel humour.

Today we see a rise in the number of disability related hate crimes and the tendency for people with disabilities to be the butt of some comedians' misguided 'jokes,' and could be forgiven for wondering if we have made any progress at all.

As a nurse, working in the often nightmarish mental handicap hospitals, David treated patients with a rare respect. He knew instinctively the truth of what Wolfensberger, the architect of normalisation and icon of the hospital closure movement, had preached: hospitals were for sick people. These people were not sick. The hospitals were the right answer. To the wrong question.

But despite the serious nature of his work, and the emotionally stressful nature of the world in which he chose to move, you cannot talk about David Heffer without remembering his wonderful anarchic sense of humour. As a student he was always at the centre of riotous pranks. He once went on a climbing expedition – an ascent on the dangerous sheer face of pavement of the local High Street. On another occasion he organised an unforgettable birthday party for himself and his friends. It must have been quite a shock for Ronald McDonald when he turned up to see them tucking into their Happy Meals!

I still find it difficult to believe how much David packed in to his short life. At one point he managed to fit in a stint of living in Australia where he managed a service for people with learning disabilities.

As a Senior Residential Social Worker in West London, David was responsible for assessing a group of people who were moving from a huge Victorian institution back

into the community, and ensuring that the move went smoothly. He was temporarily living back at his Mum's house when he first started there and she remembers him getting up at 4 am to set off for the hospital. Few people have seen such places. It was about that time that the film 'The Silent Minority' had shocked the public with its scenes of people with severe learning disabilities spending their lives rocking and grinding their teeth in hospital wards, being lined up for the shower trolleys and treated like something not quite human.

This was David's reality, and he never lost sight of the fact that these 'patients' were human beings who deserved a better quality of life.

David was killed by an IRA bomb which exploded in Covent Garden in 19??

Allan's novel *Tasting the Wind* is available from Amazon, price £11.20 (incl. p&p). ISBN 978 1 84923 380 4

When the team was eventually assembled we followed in David's footsteps and continued with the assessments. In those days many of the recognised assessment tools were no better than catalogues of failure which told us what people needed and what they could not do, rather than focusing on their gifts and qualities. David designed an interview system which asked everything – from what a person liked and disliked to what they had for breakfast and what good things people said about them. It pre-empted much of what we now call 'person-centred planning.'

His attention to detail raised the awareness of those who worked with him around issues we did not even know existed. We thought we were providing a non-institutional lifestyle for the people we worked with. It took David to point out that the bungalow had an office which only staff used, that it had fire alarms, was adjacent to a day centre, and had shift patterns which, if we were not careful, would dictate people's bedtimes as clearly as had any hospital rota.

Staff meetings took place in the lounge of the bungalow and, even though none of the residents smoked, staff would not think twice about lighting up during staff meetings.

Long before there was any talk of bans in public places, David had an uncompromising attitude toward smoking. On one occasion we had set off in a minibus to do assessments at the hospital when one of the staff lit a cigarette. Without saying a word, David removed the cigarette from his mouth and threw it out of the window. What strikes me thinking back about that was that no one batted an eyelid, thought him rude or over the top. This was David and, despite his normally laid back, egalitarian style of management, we came to expect the unconventional.

When I first met David I had recently graduated and thought I knew a thing or two about English literature. I soon found that David was one of the most widely read people I had ever come across with a real passion for John Fowles.

'Passion' is a word well applied to David because he was passionate about everything he did, be it his reading, his devotion to his beloved Arsenal or his uncompromisingly person-centred approach to his work.

One of the least materialistic people I have ever met, he lived for a while in a squat, which to me at first was a bit of a shock. I was further traumatised when he gave me a copy of *The Squatter's Handbook* and suggested I try it. Where I came from in the North West people either rented or, in increasing numbers as this was the Thatcher era, owned their own houses. Not so in Thatcher's London where the cost of living and the housing boom kept property well out of reach for anyone on a care worker's wage. But David liked to travel light and the lifestyle seemed to suit him. He would go where he felt led, live how he wanted to, then sell up and move on.

When I moved out of my council-subsidised carers' flat, David moved in. We hadn't consulted the social services accommodation officer whose job it was to accommodate people moving from outside London for a short time. "He'll understand," said David. "He's a Buddhist". And he did.

So David moved in, bringing with him his mattress, one of his prized possessions. Not that he had many or attributed much value to possessions. The last time I saw him he was sitting on his mattress sorting out his music cassettes. He was selling them, and just about everything else he owned, so he could go on his travels.

Originally he had intended to go to India. As it turned out he and his girlfriend, Robyn, traveled around South America.

Shortly after his return, David went to see an old friend who kept a pub in Covent Garden. They loved nothing better than to have raging political arguments. As an avid newspaper reader, David was always well informed and took no prisoners.

By that time I had moved back to the North West. I remember chatting with my wife in front of the ten o'clock news when I was startled to hear a name I recognised: David Heffer.

His friend recalls how they had talked that day, and he remembers getting up to collect glasses when an IRA bomb exploded behind where he had been sitting. David took the full force of the explosion. He died the next day.

David was only 30 years of age. It took a coward with a bomb to end this amazing life.

### **David Heffer's legacy**

In these days of funding cuts we need people like David who will never lose sight of the fact that people, regardless of their level of disability, are our brothers and sisters who have a right to a meaningful and valued life.

But despite our loss, a presence like David's does not simply vanish from view. Like a stone thrown into a lake, the ripples go on long after it has disappeared. A few years ago I was chatting to someone on a course in Manchester and soon realised that they had worked with David shortly after I had left. When I mentioned his name her face lit up. She told of how he had accompanied people with learning disabilities to a restaurant in West London, a favourite haunt of the well-heeled yuppies of the time. The business types were clearly prejudiced and complained about David and his companions.

Another friend of David's wrote to me recently: "I was working with Mencap at the time of his death... some pictures used in the national press were of Heff on a camping trip

we arranged and he volunteered his support. He was that sort of man".

So David went back with his friends again. And again. These days this may not seem particularly remarkable – until you realise that the integration of people with learning disabilities into mainstream settings was a comparatively new thing and that the systems of segregation had been as effective as apartheid.

When I wrote my novel *Tasting the Wind* it was natural to base one of the central characters upon David. I published it as 'Print on Demand,' which meant that I had to do all of my own marketing, including every internet outlet I could find. Then came the day when the marketing paid off in a quite unexpected way: I received a message from David Heffer's mum. Can we meet?

We met and spent the most amazing evening just talking and looking at photographs. There were photographs of David from all corners of the globe. There was a photo of him in a programme from his beloved Arsenal, passionately cheering his team on, of him with his Dad in Australia and another of him learning to play a saxophone.

She told me how, having survived acute childhood asthma, he had also survived a serious motorbike accident when he was living in Australia.

Someone who knew him when he worked in Australia wrote to her with this anecdote:

"When David lived here and ran the 'house' in Bayswater, we used to meet once a week at the pub and have dinner somewhere. One week he told me how he was upset that it was too obvious where the 'people' lived because of the minibus parked in the garden – he felt this made them stick out in the community. He'd asked the powers that be to get rid of the bus and let them have a couple of large cars. They turned him down. So the following week he turned up a bit late looking bruised and battered. When I asked him if he was OK he said he was fine but had been involved in an accident. He had dropped the people off somewhere and then had to find a car park for the bus. On turning into this car park he had 'accidentally' hit a wall and written off the bus. Needless to say, they ended up with two large cars".

I don't know much about the time that David spent in Australia. What I do remember is that at that time it was still common there for people with learning disabilities to be referred to as 'retards'. David was appalled at this and made his feelings known. Whereas it may have been acceptable at some point to refer to people in this way, as it once was to call them 'idiots' and 'imbeciles', language is ever changing, and many words from the past have changed from being medical categories to terms of abuse.

Shortly after David died I wrote a poem about him and about how I felt about the manner of his death. It was stark and depressing. It described his life as a book which should have been much longer but to which nothing could ever be added.

I was wrong.

Every year, on Remembrance Day, I remember David as a fallen hero. Once a year a group of people who were student nurses with him get together and at some point in the evening drink a toast to him.

I did not have to think twice about who I would write about when I saw the subject for this essay. The standards of practice I first saw all those years ago still inform the way in which I work.

It is unfortunate that the politically correct movement, or more accurately its extremes, has been responsible for turning itself into an object of easy satire and, in the process, obscuring some of its most important, most essential points.

David Heffer understood the relationship between language and discrimination, how it is an important part of the process whereby people lose their identity and become a group, how the stereotype becomes a joke and how the jokes accompany marginalisation and worse..

Although David is not physically with us today, I know that his spirit goes on in all of those he touched, and that his example still inspires many of us to look beyond the labels, the differences, and the cost.

I still feel that David's loss was meaningless and that if he were with us now he would be a leading figure in the ongoing fight for the rights of people with learning disabilities. But in his absence I believe that his legacy goes on. And we, and those we serve, are the richer for it.

Allan's novel *Tasting the Wind* is available from Amazon, price £11.20 (incl. p&p).

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