

Groundbreakers: Voluntary Sector Women Leaders

Women Leaders Network

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“Smashing - not Breaking - the Glass Ceiling”

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Thank you for inviting me to your Groundbreakers lunch. As strange as it may seem, for someone who is known as the disability world's chatterbox, I have never been asked to be an after dinner/lunch speaker! My biggest fear is that you will find the pudding more interesting than the speaker!

So today, I am amongst voluntary sector women leaders. It is a nice place to be. In many ways it feels like, I have come home to see my old friends, having been away at college. I will tell you a little bit more about ‘College’, (or should I call it Posh Hogwarts), later. However home, is where the heart is, and I can honestly say, the secrets of my career success, can be found firmly in the voluntary sector. It is where I learned my most valuable lessons of

resilience, negotiation, patience, and when needed, downright bloody-mindedness! Most importantly, working in the voluntary sector taught me how to listen properly and do something with what people had to say.

So here I am, home again, wondering just how on earth I managed to find myself with a title like Baroness, working alongside men in fancy dress, in an office painted in gold leaf with a throne at one end. Now I know we women who manage to climb the greasy poll, often feel we are in the wrong place; that we are flukes, who at any moment will be exposed as frauds! But believe me, this takes the biscuit!

It has been a journey of, tremendous successes and bitter disappointments, of great joy and deep sadness; most importantly it has been a journey of enlightenment.

When I think about my life over the past 50 years, I see it could have gone in one of two directions: one, a grey prospect predicted and presupposed by society; the second, a brighter future, in which I was empowered to defy all of society's predictions. I am happy to say I took the second. I want to share with you today

what enabled me to take that path. What enabled me to break through the glass ceiling, which for a disabled woman isn't a glass ceiling it's a concrete block that needed smashing, not breaking.

Well let's begin at the beginning. When I was born my mother was told to take me home and enjoy me, as I would only be around for a year – at best three. She was told that I would need intensive nursing care, and that I would suffer intolerably from lack of mobility. The chest infections that I would undoubtedly face meant that my suffering would be unbearable. The view was that my death would be a merciful release. Not a good start in life. So the first fork in my life's journey revealed itself. Would my parents accept the predictions based on my diagnosis, or would they go against the grain and fight for my life? Thankfully, they fought and here I am at 50, still unable to move or breathe without assistance, but intolerable? No way.

My parents were unusual. In the late 1950s, the doctor's word was god's. There was little expectation for any child born disabled.

There was no support for parents raising a severely disabled child.

This was the next barrier to be faced. How on earth were my parents going to raise me? Mainstream schools were not

accessible. The only option was a segregated special school for what was termed to be “incurable, handicapped children”. So I went to that school! There was nothing special about it! Education was not on the curriculum. It was a holding bay for children expected to die or, if they lived, go into institutional care or back home to be with Mum, Dad and day-time TV.

Although school education was virtually non-existent, my black and white life changed into colour when I got home. My parents painted a bright future for me. They told me that I would go on to do great things. They told me I was beautiful and that I had many talents. They dragged me to museums, gardens and playgrounds and, whenever someone told my father that it was not suitable for me to come in, he soon changed their minds. He was a 6’2”, handsome ex-paratrouper who wouldn’t accept “no” for an answer. A formidable man, although I probably shouldn’t recommend a biff on the nose as a strategy for inclusion! In a nutshell, my parents did not see me or treat me as sad or tragic. They treated me in the same way as my non-disabled sister – a child with everything to live for.

Disabled children need a positive self-image reinforced time and time again as they grow. I can honestly say that at 50 I still feel beautiful, and invincible when it comes to illnesses.

So I left school at 16, alive, bright and uneducated. I could make plasticine dinosaurs but I could barely read and write. So here was the next fork in the road: would I follow many young disabled adults to the local day centre? Or could I smash through the next barrier and get a real education. Luckily for me, it just so happened that a year before my 16th birthday, Hereward Further Education College had opened in Coventry with the specific purpose of giving children from special schools a chance to gain academic qualifications. What an indictment. That a college had to be built in order to put right the failures of the special school system! That college enabled me to overcome the barrier of a rotten education. I gained 'O' and 'A' levels with joy and enthusiasm.

From there, I went on to university and the next hurdle: living independently. Again, this was a barrier to be negotiated. There was no such thing as personal assistance or even basic access to classrooms, libraries or, most importantly, the student bar. I searched for a university that would take me on. Most didn't mind

the “walking wounded” and the partially sighted, but (as they put it) people like me needed specialised help. In the end I found a polytechnic who said they would give it a go. I used my mobility allowance of £25 a week to pay a cleaner who serviced the halls of residence, to get me up in the morning, and her daughter to put me to bed. The daughter was 14. In between, I persuaded with my usual charm, volunteers to cook for me, pop me on the loo, mend my wheelchair – in fact all the things I now pay my personal assistants to do. But it all was a struggle and I would often be left in bed or on the loo. My diet was even more hit and miss than most students. Whilst they took the stairs to the refectory, the accessible route was a half-mile detour I often couldn't manage. So I lived on Marmite and toast. Marmite – you love it or hate it. Now I hate it! University living was only just possible. Inheriting my father's bloody-mindedness got me through it.

I think my university experience made me understand the imperative need for independent living support. For disabled people to enjoy a level educational playing field, personal support and peer support can make or break this life chance. In overcoming the barriers to independence I was able to draw on my upbringing and, most importantly, the shared experience of older

disabled people I had met at Hereward college. Not all of them had come straight from school. Many of them had experience of surviving in a world before the Disability Discrimination Act. In fact, before the words “disabled” and “rights” had ever been linked.

So, here I was: a young, disabled woman, ready for work. It didn't start well! After attempting to get a job in the Civil Service, local government, and further education as a researcher -- and being rejected time and time again -- I thought I might try going somewhere where they were meant to help disabled people rather than reject them. Success! I got a job, but it was my first encounter with a charity FOR disabled people.

I have to say that it was not the best job. I had entered a world of: “We know what's best for you”. It was a traditional charity, run by the great and the good, who wanted to help and be recognised as helping, but were not so keen on supporting disabled people to help themselves – and more importantly, to speak for themselves! Out of 50 employee's only myself and one other were disabled. Indeed, I wasn't quite sure why they employed me! When I arrived I was asked to type on a manual typewriter (the keys of which were so heavy, it took me an hour to type one letter), and file

papers in cabinets I could not reach. The truth is, they hadn't thought through what an accessible work environment might look like. They could preach about the employment of disabled people but were at a loss when it came to practice. After six months they called me into the office and told me I was pretty much unemployable and I should consider doing an Open University course. This was a low point in my life. I felt if a charity for disabled people couldn't employ me, I was pretty much stuffed.

Thankfully, two important events coincided. Firstly I went to a lecture delivered by Prof Mike Oliver, on the Social Model of disability; and secondly I happened upon an advert in a magazine called Disability Now, calling for disabled people to join a progressive equality unit at the Greater London Council. The Mike Oliver lecture explained the notion that disabled people were largely disabled by inaccessible environments and negative attitudes, and not by individual impairments. He went on to proclaim that if disabled people wanted a slice of the cake and wanted to be treated as equal citizens, we had to fight for rights, rather than sit around waiting for people to give us charitable handouts.

I remember the light bulb moment as I sat enthralled. The following week I applied to the GLC with renewed ambition and landed a job as an assistant local government equality officer. I was educated to develop anti-racism and sexism policies, but most importantly I was asked to help create something similar for disabled people. Suddenly everything fell into place.

I no longer needed to struggle to fit in on other people's terms all the time. I could start laying down some terms of my own. In the same way that women were demanding flexible working and childcare, so they could work, so I demanded an accessible office with an electric typewriter that I could use to type reports at the same speed as my non-disabled colleagues. This was my liberation moment. I no longer felt guilty for what I couldn't do, or for asking for basic life and limb assistance. I began to feel I should have rights of access and inclusion, and recognition of my contribution as a disabled woman.

Understanding the social model, together with an employer who understood that equal opportunities went beyond issues of gender and race discrimination, gave me the intellectual tools to see that

disability was a form of social oppression and not something to be individually endured.

So what came after the light bulb moment? Well, I got angry of course! I became sensitised to all the barriers that existed to disabled people's life chances. Simple things like no freedom of movement due to No accessible public transport. And more complicated problems like attitudes that gave people permission to say "you can't come into this public building, because we don't want people like you upsetting the other customers or causing a fire risk" (common excuse for exclusion).

I needed to channel my anger in something productive and proactive so I joined the Disability Movement. It's slogan – "Nothing about us, without us". What followed? A decade of high jinks – I was in my mid twenties, and I was among the first disabled people to take direct action. It was not uncommon to find me sitting in the middle of Westminster Bridge with twenty other wheelchair users, bringing London traffic to a standstill. Within a decade, thousands of us had been transformed from charity victims into guerrilla warriors! We were out and we were proud! I

look back and realise this episode was crucial to giving disabled people a new identity. We were now a movement fighting for civil rights, we would never be seen again as just a homogenous group needing care and charity. Again, my predicted life course changed as a result of this political identity.

I was fortunate to be part leading the campaign to get the Disability Discrimination Act on the statute book. Working for the GLC gave me the tools to understand committees, how to put forward proposals and negotiate good compromises. All this experience gave me a taste for legislation and working with the parliamentary process -- handy skills for the future! At the same time as securing the DDA, I was also campaigning for independent living support. I knew that we were winning better rights of access to goods and services, education and employment but what was the point of all this access if thousands of disabled people were trapped in their homes dependant on others to get them out of bed! We still face the challenge of being in control of our personal support. Until the mid-80s people like me have two options. Institutional care or home support services that got you up at 10 and put you to bed at 5. Not great if you have to be at work by nine. I was lucky, I had a

very patient and supportive boyfriend when I got a job, who managed to give me just about enough support to get by, but it could have so easily been another story.

I felt by this time my journey had taken another turn. As I began to understand clearly that the personal was the political, and I was able to use my experience of needing significant personal care support, to inform my political and legislative ambitions. The challenge now was to get recognition for this new set of skills. I, co-founded the National Centre for Independent Living to support disabled people and their organisations to develop independent living and fight for Direct Payments Legislation. We achieved this law that allowed disabled people to have the money for their support paid directly to them so they could employ personal assistance. And here we have a living example of one today! At last severely disabled people like me were in control of our lives 100%. My life course yet again took another turn.

By the time I was 40 I thought I was ready and able to take a leadership role beyond director of a small voluntary body -- however effective we were. This was another concrete ceiling to be smashed through – I applied for CEO positions in the public

and voluntary sector, but each time I lost out to an able-bodied white man! And that's when I first began to experience the dual challenge of being both a disabled person, but also a woman – because it was only then that I experienced what I felt was sexism and disabalism.

I am happy to say this ceiling was broken for me by Jackie Smith, then Minister for Social Care. She appointed me lead the first Social Care Institute for Excellence as executive chair. She was a woman with vision, who felt for the first time that those with experience of using social care should help inform its policy and practice. Obviously I needed to also demonstrate the governance skills necessary to undertake this role professionally. On arriving I found not only were there no disabled people in this new senior world of running organisations but also there were hardly any women.

We don't often talk about dual discrimination. Traditionally, there has been a tendency to view disabled people as one homogenous group with no gender distinctions. To a large extent, the reality of being a disabled woman and having a physical disability, has been overlooked by the feminist movements. However, there is little doubt that the dual discrimination of sexism and disabalism places

disabled women in a doubly challenging position. And I found some real challenges, believe me!

The first one was getting my colleagues and new peers to not only look beyond the disability and the gender, but also (because I was running a social care research institute) getting them to see me as their leader not their client! For the first two years I did not mention or become involved in any strategic work on disability. I concerned myself with governance matters and ambassadorial leadership, and long-term strategic planning. Like so many women, I had to deny my identity in order to prove, I could fit in with the predominantly macho culture.

What helped me at this point in my career was something I am sure a lot of you in the room have sought out – a good executive mentor. I found the best and over five years she helped me make the very complex transition from avid disability campaigner and lobbyist, to corporate executive, without losing my USP. At the end of my five years, I had not only developed a robust and successful public research and practice institute, but I had learnt to behave myself! What do I mean by this? Well I learnt the rules of public service leadership and management. For this I was awarded the

DBE and went on to smash the final ceiling. And here I am today. I sit with you as a Parliamentarian, still pinching myself, wondering when someone's going to find out about the plasticine dinosaurs.

Since being in the House of Lords I have had the privilege to amend critical pieces of legislation, recently the Equality Bill and the Personal Care at Home Bill, hopefully making them better, more fit for purpose. I hope my experience helps the upper chamber to ensure our public service legislation, is more relevant to the lives of those it touches as I bring the voices of disabled people into our democratic processes.

Like me the House of Lords, has also suffered from stereotyping. Most of us do not live in castles, spending our vast expenses on duck houses and hanging baskets. It is a place of work. Hard work. Last week I was debating amendments to the Equality Bill until 10:45 PM, after a day Chairing an all-party group and holding meetings to hear the views of carers who wanted to influence the Personal Care At Home Bill. We do have our surreal moments however. -- Ermin entangled in my wheels, 92-year-olds racing past on scooters to beat me into the Chamber, where there are only three parking spaces for 10 PEERS on wheels!

Yes, groundbreakers, my journey could have gone two ways. One would have been a very short life, and if I had lived, a pretty narrow one. The other life, the life in colour, the life of Monty Python moments, has only been possible by the removal of barriers and a different human response to my label -- life limiting, progressive, spinal muscular atrophy.

What I hope you will also take away from my story today, is that what helped me get a different label – 'Member of the House of Lords', are much the same things most women leaders need to break the glass ceiling: -- good education; people who believe in you and have aspirations for you; role models; peer support; learning from other women who have reached the top of their profession; **and above all, the confidence which comes from an understanding that it is not your own failings which are holding you back but the barriers that society puts in your way.** I made that journey and survived. I think that allows me to change the old adage: breaking the glass ceiling, to smashing it, Don't you? (3,403)