

WHERE IS YOUR HELPER?

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I N T R O D U C T I O N

I am currently doing a part-time Masters Degree in Women's Studies at the Institute of Education in London. I am on a wheelchair due to cerebral palsy and I use a voice synthesiser (an aid for communication). I have focussed my study on disabled people. From my study I learnt that after 1981, the year of the disabled, disabled people got more assertive and empowered to fight for their own rights and disability was no longer seen as a charitable cause. People with disabilities formed their own groups, like People's First, Disabled People's International. With the formation of these groups, disabled people realised what they were missing out as citizens of a country. Let us first look at what is citizenship.

W h a t i s C i t i z e n s h i p ?

Citizenship has become the current buzzword, as politicians, academics and educators frequently use it (1). Citizenship is at the centre of the debate, making us understand what is 'society' and 'citizenship'. What is the difference between society and citizenship? Is everyone a citizen and a member of society at birth?

An ideal society caters to all its citizens regardless of gender, age, class disability, ethnicity, and sexuality. All policies, be they economic, political, or social, should be accessible to **all** members. However, we find that majority of societies do not integrate certain members of society. They do not make the necessary provisions to accommodate **all** its citizens. Such a utopian society including **all** its members does not exist. Marshall and Bottomore write: Citizenship is a status bestowed on those who are full members of a community (2). Citizenship is not connected with the various economic levels, although 'the inequalities of the social class system can remain only if equality of citizenship is recognised'.

My perception of citizenship is a sense of belonging to, or membership in, a specific society or country, regardless of gender, age, ability, sexual preference and race. I feel acutely that marginalised people are essential and contribute to the plurality of a post-modern and multi-cultural society. 1981 was declared as the Year of the Disabled. With the formation of DPI and other disability groups, disabled people became more active and are making their own decisions and fighting for their own rights and entitlements.

M O D E L S O F D I S A B I L I T I E S

In today's post-modern era, a new approach to disability has emerged over the past 15-20 years. It is usual to talk of four models, the medical, individual, charity, administrative and the social model.

M e d i c a l M o d e l

The medical model focuses on the dysfunction of an individual. In the medical model, a disabled person is primarily seen as a patient who needs treatment and medical attention. In this model the physical, mental or developmental impairment is located within the individual and serves to restrict or marginalise the individual (3). The medical model has three sub-models, which are the individual, the charitable and the administrative model.

I n d i v i d u a l M o d e l

The individual model primarily sees disability as a personal tragedy and from an individual perspective. Disabled people are considered to be passive, inert, and dysfunctioning. It is supposed to be our personal individual tragedy that we have a disability.

C h a r i t y M o d e l

In the Charity model, disabled people rely on others for custodial care and those benevolent people who are giving the 'custodial care', consider themselves as doing charitable work. In the charity model disabled people are made to feel grateful to society for their effort to be included (4). This model is characteristic of the study of psychology that explores the impact of the impairment of an individual (5).

A d m i n i s t r a t i v e M o d e l

The Administrative model looks at rehabilitating the disabled person in all spheres of life. The model focuses on getting the disabled person the 'right kind of treatment, care, and rehabilitation.' This model is primarily medical, although it has glimpses of the social model. The administrative model is essentially bureaucratic, as it looks at the costs that a disabled individual may require. To me, this model tries to normalise a disabled individual as much as possible. In Britain especially, the administrative model exists within the welfare state (5).

S o c i a l M o d e l

In the social model, the impairment of the disabled person is not seen as a problem but the economic, political and social structure of society which impedes or hinders the individual, are the problems. It is the external environment that should be modified to suit the individual with disabilities. Rioux and Bach (6) write that the social model of disability is a culmination of social, political, and legal structures of society rather than an inherent feature of an individual.

In the social model, a wheelchair user is handicapped by steps and not by his/her inability to walk. The problem is not entirely due to the impairment of not being able to walk, but also the physical construction of the environment. Swain et.al. (7) argue that if there were to be complete access for wheelchair users, then their disabilities would disappear and non-disabled persons would be more at a disadvantage.

In the social model, disabled people feel more empowered and accepted as citizens do. We realise that although there is an impairment within us, the problem that disables us further is external and attitudinal barriers. DPI have drawn up seven basic needs: Access to Information, Access to all public places, Access to housing, Access and availability of Technical aids, Personal assistance, Counselling facilities, Access to public transport. It is now accepted though not fully practised, that only with full access to public facilities and with disabled people being placed in decision-making positions, that disabled people can be regarded as equal citizens.

In this paper, I will also address my experience in higher education in the UK, within the social and rights model. In the social model there should be a mandate that all higher education institutions have the following pre-requisites:

- ACADEMIC ACCESS
- ACCESS IN THE ENVIRONMENT
- ACCOMODATION
- PERSONAL ASSISTANCE
- ATTITUDES

I shall give you a personal account of the difficulties I have found from a perspective as a Cerebral Palsy Person.

A C A D E M I C A C C E S S

At my university in London, both the Computer Centre and the Library are accessible and the Librarian was very aware of the needs of the disabled persons and has made most of her staff aware of these needs. The only problem is that I find I cannot access those books, which are beyond the level of my wheelchair. As the course progressed, I found that I needed to access specific books and journals on the internet, but my physical disabilities impeded me in many ways. I was not able to take the details of the location of the books from the Libertas system in the Library, as I could not write with a pen or pencil. Nor could I keep in my memory the details of more than one book. I could not photocopy, as it needed tremendous bilateral skill of both hands. The photocopier was not accessible to a wheelchair. Therefore, I could not use the photocopier. I needed a person to give support by writing the details for me. I asked the Library staff who were very friendly, very supportive, but since I was the only one asking for this and did not quite fit up to the norm, I began to feel embarrassed which led to a feeling of guilt, leading to a disinclination to ask for this help.

Being a tenacious and forceful person, I asked as much as I could and was helped by the Library staff. I was very fortunate in having a Library staff who interacts with me positively on every need.

However, I feel that students with problems of hand function and speech could have a person who could be in the Library, and who could be allotted the tasks of specifically helping the student with academic matters needing effective good hand function, such as accessing library books. The photocopier could also be modified so that it is on a lower level for a wheelchair user. I found most of the staff helpful but some did not like to be disturbed despite the need to access the photocopier, remembering that copies are critical needs for academic work.

P a r t i c i p a t i o n i n C l a s s

In the class, I asked another student to use a piece of my carbon paper while she took lecture notes and found nobody minded doing this. I also used a tape recorder sometimes to record the whole lecture. I would always have to pre-plan the recording of any lecture.

On the first day of the course, I was asked by my tutors to prepare a brief introduction of myself. Through the voice synthesiser, I described my physical disability. There was a great deal of interest in my story.

For the first three seminars, so that I could participate, both my tutors had emailed me the questions before hand. This gave me an edge over my peers. It also made my peers understand that I was a thinking member of the team. In these weekly seminars, the tutors told us that an effective way of learning would be to form reading groups. I got myself into one, with four other students; being in a smaller group allowed me to contribute. During these sessions, I used my voice synthesiser a great deal.

P e e r - s u p p o r t

This was the first time in my academic career that I participated and interacted with my peers on an intellectual level. Encouragement and guidance from my tutors, invaluable peer-support and the healthy competition, helped me to go through the course and spurred me on. I took one module of study in "Women's Studies: Feminism and Disability". For one of the seminars, the topic was difference and diversity. The word 'difference' being used to describe the difference between women themselves as well as opposed to the differences between the two genders. Initially, Women's Studies implicitly was for only white, middle class, heterosexual able-bodied, western women. Women's Studies previously did not explore women from different class, ethnicity, colour, disability, sexual preference and age.

A C C E S S I N T H E E N V I R O N M E N T

Environmental access... lack of a Hall of Residence

Fred Wilenius suggests that the notion of environment can be confusing, ranging as it does from the very broad, 'the environment', to a very narrow view as something very immediate and personal (8). I would go further in describing the two conceptual levels of environmental barriers. The narrow being the 'immediate barriers' (8) of access such as accommodation and personal care support and the broader affecting the student's quality of life such as student-tutor relationship, peer group interaction and the student's relationship with the university management, socialisation patterns, which makes University life exciting.

In Oxford, there was accessible accommodation for students with disabilities. However, my college in London had not yet addressed the problem. I had lived in a student accommodation for two years before I began the Masters programme with a family member, but when I applied for the same accommodation as a Masters student there was a bit of an uproar. They were not willing to take any responsibility for me in the Halls of residence, as I was a 'disabled student.' The higher officials thought that I needed specialised housing, specialised care, and special handling. An important member of the team was keen to put me into a care home for 'the disabled', which was some distance away.

This would have been impossible for me as most of the care homes for the disabled persons are placed in the suburbs of London and access to public transport for wheelchair users is poor. In London, a disabled person has only access to taxis. Besides the taxi service, there is also a "Dial-a Ride", which is a mini-van, and a disabled person can have unlimited amount of rides.

Other members of the team suggested that I try private accommodation. The suggestion of asking me to find private accommodation implied two things. First, if I were to live in private accommodation, then it was only my personal problem rather than the University's. A crucial factor to take into account is that some lectures were in the evening. Therefore, if I lived outside the university area, I would get home very late which affected my carer and also the long journey would tire me out.

I also tried other university's hostels within the area of central London, which had accessible rooms and toilets for wheelchair users but found some excuse for not accepting me into their accommodation. Their standard phrase was "what would happen if there was a fire". I found great discrimination in this matter, as the other residents could not be asked to give me a hand in case of fire. All doors for accommodation seemed bleak. No one wanted me. That is why there were not many disabled students within the area of central London. It is vital for disabled students to have accessible housing within walking distance to the university, so that a disabled student has freedom to access the university's facilities whenever he/she wants to.

There was also an issue about my fee status. Overseas students were supposed to be Full-time, and I due to my slow speed at the keyboard could only do the Master's part-time. After much discussion amongst the higher officials of the Institute, I became the first part-time overseas student. After much discussion convincing the administration that I would not need any extra help, the flat was allotted in my name. I had a place on the course and a place to live, it was a major battle that I had won.

P e r s o n a l A s s i s t a n c e

I only needed a carer for one hour in the morning and one hour in the evening. For the first time I had to cook for myself as my evening carer came from Nigeria and knew how to only make Nigerian food! I used to tell my carer what I wanted and how to make it, by telling her exactly what to put into the dishes.... A step-by-step cooking process, which she vastly enjoyed. My cooking was not great, but edible. The most important factor is not the amount of physical tasks a person can perform, but the amount of control they have over their everyday routine (7).

A T T I T U D E S

I had had some experiences of living independently. I cherished the experience of being on my own and for the first time I did not have to tell anyone my whereabouts. This kind of freedom was new to me. I felt euphoric at attaining it, but at the same time, I felt it was a huge kind of responsibility, as I felt that everyone was watching me and waiting for me to falter. Although I had the freedom, I still had boundaries and limits, like I knew that I had to be back at seven- the zero hour, when my carer used to come and give me a helping hand with my nightly chores.

A few people made comments like: 'Aren't you marvellous living and managing on your own? How brave you are!' Do the non-disabled persons have these questions hurled at them? I wondered. My friend who was with me said, 'what is so brave about living and managing on her own, all students manage on their own.' Some people made me out to be a 'supercrip'! (or a super cripple). I was frequently asked by a couple of the Institute staff 'Where's your mother?' in a very solicitous and helpful tone. It really annoyed me. Was it because I was on a wheelchair? How could anyone ask a thirty-three old, 'where is your Mummy?' Did they think I was an infant? Did they have no other conversation to make with people like me? Or, if they knew I was on my own they asked me, 'how do you manage?' I wondered what gave them the right to invade my privacy. Was it my disability?

A while ago, I was going up in the lift at the Institute to attend a seminar. As I got into the lift, and uttered the word 'six' (yes I agree that my speech is not the world's best and I have particular problems with the s's) one woman looked at me and was very agitated and asked "Are you alone, where's your Helper?!" I was horrified and angry and said 'I don't need a helper'. Luckily for me, I did not have too much time to talk. The lift stopped at the sixth floor. I whizzed out and narrated this incident to my tutor and my peers, who were more enraged than I was, about these questions. We never ask the able bodied such questions!

The other incident happened a year ago when I decided to go to another student canteen for lunch. I went in and stood in a long queue. There were throngs of freshers all in line queuing up for food. I took my cutlery and was waiting my turn to be served. In my mind, I finally made the big decision of what I was going to

have. I envisaged difficulty in communicating what I wanted but I went alone with the crowd. A young man in his thirties came up to me and offered his help. I accepted it with alacrity not knowing the consequences. He ordered a chicken korma and chips for himself. He turned to me and said, 'Can I help you?' 'I want chicken korma and chips too', I said, and also gestured as it was on the board. The young man told me to go and sit while he got the food. I found a table. The food arrived. I managed to tell him to cut it up.

A friend of his came to our table and said, 'she can't be alone, she doesn't know her mind. I have worked with these kinds of people before. These people do not know their mind, they are mental'. She was young, quite attractive, wearing jeans and a T-shirt. 'Who are you with?' said my man companion anxiously. He was in his late thirties. I gestured to him in between mouthfuls to please go and sit with his friends. 'Who is with you?' The girl asked again. 'No, I am on my own.' I said with great conviction but it was useless. 'Can I see your bag.?' She asked me loudly, as if I was deaf. 'No you can't,' I said. I really felt like an old woman that refused to part with her bag. There was something about not wanting to part with one's bag, - someone taking your independence away. 'I am ok. Please don't worry about me. I am alright on my own,' I said forcefully but it was pointless, as she obviously did not understand my garbled speech.

'I am going to call the management', she said to her man friend forcefully. Reluctantly, I let go of my bag and took out my purse. My purse had only the cards of my Bombay address, which was probably a good thing. 'Are you a writer?' asked the man friend. 'Yes,' I said. Bravo, I said to myself. At last I thought that they had understood that I had not got a mental problem. I ate a few mouthfuls and thought all was fine with the world, but it did not last long. 'I am going to go call the management, I know what these people are like they don't know their minds. Someone must be with her. She can't be on her own, I have worked with these mental people. It can be very dangerous', the girl said, as she got up. One of the ULU security guards came with his radiophone with the girl. 'No one has reported her missing' the girl said, 'but he will look after her'. With that, she made her exit.

I finished my lunch and returned to the institute where everyone knew me and by living in the institute's premises for over year, I had become quite well-known, I thought.

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REFERENCES

1. Bulmer M, Rens AM. (eds) Citizenship Today: *The Contemporary Relevance of T.H. Marshall*. UCL Press, 1996.
2. Marshall T H, Bottomore T. *Citizenship & Social Class*. Chicago Pluto Press, 1992.
3. Beratan G. *Disability: Competing Paradigms or no Competition?* A Master's Dissertation Institute of Education, University of London, 1997.
4. Chib M. *Citizenship and Barriers*. Adapt: The Spastics Society of India, Bombay, 2000.
5. Barnes C, Mercer G, Shakespeare T. *Exploring Disability*. London, Polity Press, 1999.
6. Rioux M, Bach M. *Disability is not Measles*. The Roeher Institute, Canada, 1994.
7. Swain J, Finkelstein V, French S, Oliver M. *Disabling Barriers – Enabling Environments*. Sage Publications in association with The Open University, 1993.

Wilenius F. *The Management of University Provision for Students with Disabilities*. *The Institute of Education*, University of London, 1992.