

## GETTING THERE: NON-DISABLING TRANSPORT

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Liberating a disabling society: citizens on the move \*

Vic Finkelstein

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### INTRODUCTION

I think it will be best if I start my talk by making it clear that I agree with the view that modern societies are dependent upon 'freedom of movement' for their existence. They depend on this in several ways. Firstly, since the invention of the factory system following the industrial revolution, large scale production has taken place in locations which depend on the free movement of workers from home to workplace. Secondly, the sale of commodities has depended upon the free movement of consumers from the home or workplace to the market. With the expansion of the economy freedom to travel became a rightful way of spending income from employment in consuming leisure time and holiday activities. All of this involves a mass of movement with variable access to private and public mobility systems.

We can visualise society, itself, as a living organism with a constant stream of movement along the land, sea and air arteries. Like any living body when movement stops the organism dies.

In other words freedom of movement is not only essential for the maintenance of personal economic independence but also for the health of society itself.

This highlights the two themes of my talk:

1. people who do not have equal access to mobility systems, whether personal, private or public, are mobility disabled, they are socially dead; and
2. the existence of systems which prevent equality of access to social mobility are systems with a deficit, and systems with a deficit are disabled systems, in time they, too, become socially dead.

In the rest of this talk I will explain what I mean by these two themes.

### **The cultural immobilisation of disabled people**

In a social system where the freedom, or ability, to move defines whether or not a person becomes socially alive or socially dead there is an enormous incentive to encourage disabled people to aspire to 'normality'. At the same time there is a disincentive for the mobility systems which exclude access to disabled people to view that system as having a deficit – as being disabling.

This encourages interventions to make disabled people normal and to develop personal and public mobility systems on the basis that the users will be normal. The consequence of this is two-fold: firstly, deficits in the mobility system remain unrecognised, and an unimaginative concept of social mobility (as distinct from the technical side of mobility) is cultivated; and secondly, there is a

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restricted understanding of disabled people, and an unimaginative view of personal mobility systems is cultivated. This culture I will call “**the cultural immobilisation of disabled people**”.

### **A case in point:**

In 1988 I had an opportunity to spend a little time in two very different cities in two continents. This experience helped me clarify some of my own basic ideas about disability and the practical tasks facing disabled people.

Firstly, *Budapest*:

When I was in Budapest, Hungary, I was very interested in visiting the well-known Peto Institute. The centre is known for its approach to the treatment of children with cerebral palsy. Its central claim is that it has been successful, where others have failed, in enabling these children to walk. The approach involves systematic day-long intervention under a regime, called ‘conductive education’. This facilitates intense concentration on goals such as walking and speaking as ‘normally’ as possible.

My visit left me with several striking memories which are firmly embedded in my mind. There was the approach to the building with its main entrance **up a flight of stairs** - an uncompromising rehabilitation statement: “enter the building through the accessible side entrance in a wheelchair” and then after treatment “leave down the front stairs walking”.

Here is what I wrote soon after the experience:

Inside the building children with helpers were everywhere struggling laboriously along ‘walking’. My hosts and I waited for the lift and while we waited watched little children slowly working their way up the staircase with ever attendant ‘conductors’ (some staff, some parents) hovering over them. As we came out of the lift we could look down the stairs at the children about to have the rewarding satisfaction of having taken half an hour to reach the same floor we had so effortlessly arrived at in the lift. The thought was overpowering: “what view of disability enables able-bodied people to spend huge resources in brain-washing disabled children *against* the use of our **access-mobiles** (wheelchairs) while at the same time it enables able-bodied people to spend a fortune perfecting and promoting use of their own access-mobiles (such as motor cars and lifts)?”

It seemed to me that the Hungarian experience captured the able-bodied **eleventh commandment** “walk and then ye shall be a real person, a citizen”. This is cultural immobility, cultural numbness.

And now, *New York*:

It was in New York that long forgotten memories of being ‘normal’ were revived. For one month I rented a room in a large block of flats in Manhattan and during the working day travelled to work in the wheelchair accessible public buses. The regulation is that accessible buses must allow entry for a person in a wheelchair at a bus stop if no wheelchair user has already boarded. Passengers sitting on the fold-away seats (where wheelchairs can be automatically clamped) are obliged to move when a person in a wheelchair boards the bus. This means public transport is accessible even during the rush hours. Entering an overcrowded bus during the rush hour, strange as it may seem, was an absolute pleasure after so many years of being denied access to normal public transport. However, this is not my most enjoyable memory of being a commuter in New York. Travel does not just

mean moving from one place to another. It also entails seeing the world from a particular viewpoint and, more importantly, sharing common experiences with fellow citizens.

It seems banal to say that we make sense of our world according to the way we experience it but this principle, rather than any principles derived from the treatment of physical impairment, is basic to understanding disability. If disabled people are denied access to normal social provisions we will not only have different experiences to that of our able-bodied peers but we will interpret the world differently; we will see it and talk about it differently. This, of course, is the root cause behind the disparity between demands for new approaches to community services articulated by leading organisations of disabled people and the call for yet more resources to be poured into existing services set up by able-bodied people for disabled people.

In New York travel in public transport provided me with the opportunity to share an important daily activity with other commuters. For the first time in adulthood I felt I was experiencing the same freedom of movement in the public arena that was possible to my able-bodied peers. This common experience not only raised common points for communication (for example, muttering about a bus being late) but, more significantly, influenced my sense of equality with them.

Each day I felt confidence in myself growing and I became more adventurous in my willingness to travel unaccompanied in the city. Confidence bordered on recklessness and several people cautioned me about wandering alone in New York! I not only felt less self-conscious as an isolated disabled person in an able-bodied world but also more able to initiate and respond to conversation with my peers in the street and increasingly in other spheres of daily activity. Poorly constructed ramped kerbs, steps into buildings, narrow doorways, uneven sidewalks and inappropriate street architecture still persist in sufficient abundance to ensure that New York continues to disable its mobility impaired citizens. However, the accessibility of new metropolitan buses and access into, and in, modern buildings has been taken sufficiently far for there to be a real sense that equality for disabled people is not just a distant aspiration but also an achievable goal.

## **The immobilisation of culture**

In the Peto Institute, in Hungary, I felt there was a direct connection between this world famous institute with its philosophy and resources promoting 'normality' and the almost total invisibility of disability in the real world, out there in the streets, shops and life of Budapest. The meeting place where we discussed issues in planning services and facilities for disabled people was inaccessible, the central offices concerned with the identification and allocation of benefits to disabled people was inaccessible, the streets and shops were inaccessible, even moving about in the hotel, let alone out the front door, was difficult. After a week in Hungary being the odd one out, stared at and immobile I felt thoroughly disabled and, for me, this found its ultimate expression in the cultural immobility of the Peto Institute. In this place disabled people are 'conducted' by able-bodied 'educators' who write the score and decide how it is to be played. There are no disabled people earning their way in the world (and paying their taxes) by working in this expensive enterprise. I was most definitely not an equal. In here I was a 'person with a disability' and as an adult, if not actually a lost cause, then at best a potential case for re-education. Nowhere could I detect signs of disabled people impressing their culture, values and goals on the utilisation of resources, facilities or attitudes of staff.

For me there are two unacceptable outcomes which logically follow from a culture which regards disabled people as immobile unless they can become 'normal':

1. Resources are poured into making disabled people normal and the social and physical environment is left to stagnate. In this situation disabled people become passive and inconsequential to social development.
2. Attitudes towards disabled people become tainted by obsessive concern with 'normative' goals. Disabled people are 'prevented' from evolving any independent self-image and pride in themselves. The extraordinary intensity and time spent in trying to make disabled children 'normal' will, surely, inculcate idealised images of the able-bodied form and life style. I believe this is unhealthy both for the individual and society. What I am saying here is that critical thinking is stultified and social innovation is not on the agenda.

Any culture which rigidly believes that it is part of the nature of disability to be immobile, is itself a culture which is immobile. In this respect, the dominance of 'charity' and 'care' attitudes for services in Britain can be said to have locked our culture into an unimaginative view of the world and, from the point of view of disabled people, without a culture of innovation we will sooner or later realise that we are doing no more than surviving in a motionless, lifeless, culture.

### **Liberating a disabling society**

What a curious contradiction. In Budapest the Peto Institute concentrates on trying to make disabled people normal. The philosophy of 'normality' is paramount. As a result there is no recognition that disability is the result of disabling barriers created by a world designed for able-bodied living. The longer I stayed in Hungary the less mobile I became and the more disabled I felt – anxious, vulnerable and dependent. In New York there is a move towards accepting disabled people as citizens with normal rights. As a result disability is reduced by policies involving barrier removal in the social and physical environment. The longer I stayed in the USA the more I experimented with moving through the environment and the less disabled I felt – increasingly confident in my ability to function and pursue my own interests. For me my contrary sense of disability in the two cities raises profound questions about the way we understand disability, whether a culture is immobile, or liberated and ready for innovation. In my view the whole answer to the question of creating a non-disabling barrier free transport system resolves around issues posed by the Peto Institute; in particular: If "nowhere can we detect signs of disabled people impressing their culture, values and goals on personal, private or public mobility systems" then what strategies ought we adopt to ensure that disabled people do have an impact on the different forms of social mobility - this, I hope, is a question that this conference will consider.