

INCLUSIVE LIVING - THE WAY FORWARD

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Transport implications of care in the community

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Being Disabled

Before I talk about the implications of ‘*care in the community*’ policies for the transport needs of disabled people I think it is important to clarify just **for who** this policy of care is advocated. I think this is important because it seems to me that at the very heart of the new legislation’s **advantages** there are significant and serious **flaws**. I believe that without addressing these flaws there is little possibility of making substantial and lasting changes in the equality of opportunity for disabled people in British society.

I believe:

1. On the one hand that the overwhelming support of disabled people for the long and exhausting struggles over the past twenty years for the right to live in, and be a part of, mainstream society is now increasingly recognised in new community care policies.

This, many of us hope, will bring to an end the long and sorry history of isolating disabled people in apartheid institutions like Young Disability Units and Cheshire Homes.

2. On the other hand, I believe that able-bodied society, and particularly their representatives in parliament, still persistently misinterpret what is required for disabled people to attain their full citizenship rights as part of living in the community.

To be brief, many able-bodied people still seem to think of disabled people as if we are **able-bodied people, but with impairments**. Because the possession of an impairment, to a non-disabled person, means the inability to look and function **like an able-bodied person** this, in itself, is invariably interpreted as **the** problem; or, what amounts to the same thing, ‘*not to be able-bodied*’ is but another way of saying ‘*not to be able to function*’. The priority, then, is seen as devising interventions which can re-habilitate disabled people to able-bodied ideals. It is this view that is fundamentally flawed. While it may well be appropriate to set up programmes with the objective of rehabilitating people with impairments to an idealised able-bodied standard this approach, when applied to disabled people, can also well lead to a denial of the legitimacy of a satisfying and rewarding disability lifestyle. It encourages the view that disability is, and disabled people are, a long term social problem. From this point of view disability is interpreted as an individual’s inability to function without able-bodied care.

The philosophy behind current policy to support disabled people in the community is flawed, then, because the only real change that is envisaged is the move of ‘caring’ out of the confines and restrictions of institutional life and into the open market of community life.

The very aspect most frequently criticised by disabled people about institutions – that institutional caring can bring with it the debilitating control of others over disabled people’s lives – is, under the new policy of care in the community to be extended!

In the words of Richard Wood, Director of the British Council of Organisations of Disabled People, ‘*disabled people do not need care*’.*

Questioning a traditional identity

In my view, in questioning the identity assigned to disabled people by the promoters of the so-called caring society we need to start with the understanding that while disabled people, like their able-bodied peers, can **also** have impairments and need caring assistance from time to time, it is not at all appropriate to **characterise** disabled people as a group in terms of this care. Being a '*disabled person*' is quite a different matter to being a '*person with an impairment*'. The latter condition is something that can be shared between all human beings across class, gender, ageing and disability lines. The former condition is quite unique to this population group.

Let me explain further:

In South Africa many white people spend time in the sun trying to burn themselves a healthy brown. Sometimes those who are darker skinned worry that they might be taken for black and face the prejudices of racism and the restrictions of apartheid law. Nobody, however, believes that getting a darkly burnt skin will turn a white person into a black person. Similarly, few would believe that you can, say, become French, simply by learning the language and living in the country for a while. Yet most people, including disabled people, still believe that '*anyone can become disabled*' simply by acquiring an impairment of body or mind.

There is a singular lack of understanding that an able-bodied person with an impairment is not a disabled person, any more than a white person with dark skin is a black person, a bilingual English man or woman speaking French is not French, a man dressing in women's clothing does not become a female or gain insight into what its like to be a woman. Simulating blindness with a cloth-binding cannot increase understanding of being a blind person and playing games in a wheelchair all day does not increase awareness about the mobility restrictions faced by any one group of disabled people.

An able-bodied person with an impairment is just that – someone who looks at and interprets the world from the perspective of restrictions to their functioning as an able-bodied person. Any difficulties faced under these circumstances are inevitably interpreted as the consequence of the impairment, because that **is** what is restricting the **able-bodiedness** of the individual, and solutions to the restrictions are seen both as special forms of intervention and as compensating for the impairment of body or mind. Quite right too!

From the point of view of being able-bodied the shaping of the world according to able-bodied needs is not compensatory at all. On the contrary, making changes to the environment and the way we relate to it are regarded as the very essence of being healthy and human. A motor vehicle is not seen as a **special** aid to be prescribed by a health or welfare service because the frailty of able-bodied people gives rise to special mobility needs. Able-bodied people determine their own mobility needs according to able-bodied lifestyles, culture, ingenuity, material goals, etc.

However, learning new skills, adapting the environment or changing the rules of social interaction **because of impairment** is seen as compensatory. The prevailing approach is to analyse all the activities, needs, wishes and difficulties of disabled people – ie. the totality of disabled people's lives for those who take a holistic approach to disability – as if these are the same as might be expected for able-bodied people with various forms of impairment. Solutions to the difficulties faced by disabled people in education, employment and mobility, for example, are then often seen as a problem in assisting disabled people to cope with, manage and adapt to the able-bodied world. There seems little awareness that this approach is upside down. What is needed is the construction

of community life so that, as for all population groups, the **community is also fit for disabled people**.

Care in the community

'*Care in the community*', as a policy philosophy, is firmly rooted in able-bodied assumptions about disability. A person with an impairment may need **care**, and disabled people, too, can have impairments of body and mind. But what disabled people need, just like their able-bodied peers, is **community based support systems**. For able-bodied people this takes the form of public utilities - like the electricity supply service, postal service, etc., and of course, public transport. These utilities have emerged in the course of a long history involving the struggle of human beings to control and mould the world according to their lifestyles, culture, etc. Disabled people, until very recently, have had no say, interpretation or impact on what this world might be when constructed from the perspective of our lives and culture.

The very notion that disabled people might have a unique perspective about the community that we would like to see constructed and live in, where we might cultivate our approach to the arts, design, education, employment, public transport, and health and welfare services may seem very unrealistic. It may seem to '*fly in the face of reality*'. But fly in the face of reality is precisely what non-disabled people have done, and see as legitimate goals for themselves, when they take to the air and move through space and time far faster and in greater comfort than any of the birds that in past centuries they have envied above them in the skies.

It is the assessment of needs and the construction of care packages according to able-bodied views about the nature of disabled people's lives that is unrealistic and dependency creating. This is because it generates an ever expanding market for the employment and training of carers and an ever decreasing opportunity for disabled people to care for themselves. As far as disabled people are concerned, in my view, '*care*' and '*in the community*' are a contradiction. The policy does not, it seems to me, present us with a unified philosophical foundation adequate for the construction of effective support systems for disabled people in the community. In the final analysis this approach imposes a stultifying constraint on the ability of disabled people to have an impact on the rules for the game of being '*human*'. It restricts, for example, any real challenge from disabled people about the organisation of public life because it sees our lives in terms of an able-bodied public.

The question is '*can the objective of assisting disabled people to live more independently in the community be enhanced by responding to current care in the community policies?*'

Living in space and time

Human beings live by moving in space and time. However, these aspects of life are achieved not in the behaviour of individuals but by the collective will and action of many people sharing common goals. The modern city bus, no less than the sophisticated aeroplane, is the production of a collective will and shared experience. For many disabled people, however, these dimensions of our existence are suspended. What is undoubtedly needed, in the next phase of the movement of disabled people out of isolation in institutions, special education, special transport, unemployment, and so on, is the means to have a direct impact on the way our society plans and organises the delivery of public services and utilities. If living in the community is to have any serious meaning for disabled people then this must also mean having an impact on the shape of the community in which we live.

On the one hand '*care in the community*' will have an influence on this process because the legislation promotes the re-integration of disabled people into society. On the other hand the struggle will be to ensure that disabled people do not play a secondary role to carers in determining what community or society we should be integrated into. This will be the only way to try and ensure that assessing the mobility needs of disabled people within packages of care, for example, are not simply constructed in the image of able-bodied perceptions of mobility. What is not needed is special transport provided as a compensation for non-ability to walk.

In my view the goal should be the construction of transport systems which are adapted to disabled people's forms of mobility. I don't think this is merely a question of making, for example, buses accessible to users in wheelchairs. It is a question of looking at timetable scheduling, at bus routes, at bus driver training, at the comfort and safety of disabled passengers, at the level and presentation of sign-posting, at the street architecture where buses stop, at fare costs, and so on. It is also a question of ensuring that new levels of dependency are not developed. I can perhaps convey the size of the challenge by suggesting that one way of starting to unravel able-bodied perceptions of disabled travellers needs could be by returning to basics in transport design, but this time from the point of view of the disabled commuter. What about designing a public transport system for disabled people **and then** consider what add-ons might be needed if such a system were to be made accessible to non-disabled passengers? I am sure such an exercise would generate exciting new ways of looking at social mobility.

My one, rather limited experience of accessible public transport has had a lasting impact on my self-image, as a functioning citizen (or rather as a citizen denied my mobility rights). I believe the introduction of the system has also had a rather more subtle impact on non-disabled commuters:

In 1988 I stayed in New York for one month while taking part in a disability related project and during the working day travelled to the office 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 hour. The result of this was that on several occasions I was able to board a rather full bus while fellow commuters at the bus stop were obliged to wait for the next bus. It occurred to me that in this particular situation I, who cannot walk, was more mobile than fellow travellers who can.

While to many people an impairment affecting walking means a lack of mobility, the reality is that acquiring an impairment affecting walking only means that mobility has then to take on new forms where it can be equally, and sometimes even more, effective. If we start from this assumption about disability – ie. that disability can mean a different, but equal lifestyle – then care in the community also involves the adjustment of the community to the standards of those it is supposed to be caring about.

A lasting memory of my experience on the public buses of New York is the length of time it took to lower the side entrance chair lift, fold away the seats and ensure that my wheelchair was securely clamped. While on the one hand this was usually effected reasonably efficiently and quickly it did involve more time. I asked a fellow passenger what she felt about this. She said, and I know of no research on this, that at first able-bodied commuters did complain about the longer time it took but after a while seem to have become resigned to the implications of enabling disabled people to use public transport. 'Anyway', she added, 'New Yorkers rush about too much and perhaps it is a good thing for them to slow down their pace a bit.'

An accessible world for disabled people is arguably a better world for everybody!

Whatever, the outcome of developing the new community care policy we can be sure that the National Health Service and Community Care Act, 1990, will generate a new level of debate about the meaning of disability and the appropriate ways of ensuring that disabled people can, in reality, exercise their citizenship right to freedom of movement alongside their other legitimate rights.

* Said at a 1991 Disability Research Seminar at the Policy Studies Institute, London.