**A case of human rights**

Simon Brisenden

When we are young we are supposed to be hopeful, but many young people with disabilities

have given up hope of an independent life before they have reached their late teens.

Young people with disabilities need to know that they can lead independent lives, that they can

control their own destinies, that they can avoid the internal exile from society that has been

forced upon their predecessors. For internal exile has been the reality of much so-called 'care' in

our society.

Let us look at what the word 'care' has come to mean to people with disabilities. Let us look at

how it confronts with awesome finality the person growing up with a disability. For a start, the

person who is cared for is a nonentity, someone who does nothing all day long except vegetate

in front of the television. If you have to be cared for by somebody else you do not have a life of

your own, you do not have opinions, ambitions, desires.

I can remember in my teens wondering how I was going to manage. I thought that perhaps I would get a job and be rich enough to employ people to help. Or perhaps I would get married and have a devoted-and of course beautiful-wife to look after me. However, just like when I was at school, I must have been daydreaming when the riches and the devoted wives were being handed out, because so far I remain young, free, single and in debt at the bank.

Incidentally it is something to ponder on that if I were to get married to a non-disabled woman -

or to cohabit for any length of time - the social services would remove financial help I receive to

employ my own carers. This has happened in one recent case. The state, as always, remains

eager to exploit the unpaid labour of women.

Anyway, even while still at school I knew that I wanted to avoid the fate of those who are 'cared

for', for I realised almost instinctively that this was a sort of limbo existence, neither truly alive

nor truly dead. It was almost ten years after I left school that I found what seemed to be realistic

for the sort of independent life that I wanted.

It was then that I encountered people from the Hampshire Centre for Independent Living, a

number of whom has moved out of residential care and into the community. They had done this

by persuading the social services to give each person a grant to employ their own care support,

proving it to be a more cost-effective option that institutional care.

This was the model I was determined to follow. Indeed, it inspired me and turned my whole life

around. I suddenly realised that I did not necessarily have to be submerged in the twilight world

of those who are 'cared for'. I could actually have the personal care I required delivered under

my control in such a way that it supported rather than submerged me. I could design my own

package of care and get financial support for this from statutory agencies. This had to be the

way for me.

And - to cut a long story short - it was the way for me. Since 1984 I have been living

independently in the community of central Southampton, employing a team of three carehelpers

who are finance by my disability benefits and a grant from Hampshire County Council.

The dreams I had at school had finally connected with reality, and I have not really looked

back since.

But after four years of independent living I realise that society still needs persuading and

educating about notions of care and independence. For a start we seem to be confused about

what care is, and this leads to a society in which care is delivered in ways that are inhibiting to

individuals rather than enabling them.

The role of the carer should not be to control, but to facilitate. I define this as being the

necessary intervention enabling the decisions of the individual to be carried out. Anything more

than this is an infringement of a person's liberty.

We also need to be clear about what is meant when we talk about 'independence' in this

context. We are not talking about being able to do everything for yourself. Neither does it imply

cutting oneself off from the assistance of others. For what matters is not whether you do

something with or without the help of others, but that it gets done under your direction. Being

independent simply means that you have some control over your life, and that you do not live

by the routine of others.

Most often professionals think that teaching people a lot of stuff about dressing themselves,

making beds, cooking, washing clothes is putting them on the road to independence.

This is because those who work in the welfare professions have grave difficulties seeing things

from the point of view of their clients.

But as consumers of welfare services we can no longer be satisfied with all this being portrayed

as a welfare issue alone. It is not a matter that can be left to people who work in health related

professions. We must see disability as a political issue and not just as a welfare issue.

Whenever we are talking about people's quality of life we must try hard and remember that they

are people, that they are human and not just a inconvenient sub-species. They - I mean we – are human, and therefore we have human rights.

Living in the community is a right, not a privilege. To deny a disabled person the ability to live in

the community is a abuse of human rights.

The right to a independent life is the most basic of all rights. The most fundamental right of all is

that of living in the community alongside your fellow human beings. The only people who are not

officially allowed to do this are criminals, and we have committed no crime that I am aware of. So why are we banished from society? Perhaps the reason is that we have no political muscle, we have not yet started to demand our rights with enough firmness and conviction. Once we have started to do this and we have given up putting all our faith in flag days and sponsored runs, then we can really start to change things.

This is not just a philosophical issue, a question of political theory which is of no relevance to real life, but is obviously also a practical issue. It is about giving individuals the opportunity to design their own package of care. And this means a real commitment to community care which is properly funded and which is not a smokescreen behind which government dismantles the

services people rely on.

We have to try and make sure that the young disabled people of today still have a social

services network to call on tomorrow. At the moment not even this can be guaranteed.

*Written by Simon Brisenden, who died 1989. Simon was Secretary of the*

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