

**WHERE WILL OLDER PEOPLE BE?
INDEPENDENT LIVING VERSUS RESIDENTIAL CARE**

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**THE CARE AND MANAGEMENT OF OLDER PEOPLE WITH
COMPLEX NEEDS**

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by

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Introduction

I should make it clear at the outset that I am not a specialist in old age. I am a professional sociologist and have spent all of my working life on disability issues in general and my particular interests have been centred around theory, policy and research. So, you might ask, why have I been invited to give a paper at this conference? I think it was because of a recent Radio 4 interview I gave where I accused the Leonard Cheshire Foundation of incarcerating thousands of disabled people over the years. There are, of course, parallels here with old people as many of them are incarcerated, often against their will in institutions of one kind or another. So one theme of this paper will be to consider whether the criticisms that have been applied to the incarceration of disabled people can readily be applied to the placing of old people into what is usually called 'residential care'.

Over the last thirty years we have seen nothing short of a revolution in the way disabled people are both perceived and treated by society. Unfortunately I do not have the time to describe this in any detail but the following slogans give a flavour of these changes: 'from charity to rights', 'from exclusion to inclusion' and from 'dependence to independence' I do not mean to imply that life is now wonderful for all disabled people because this is far from the case and many disabled people continue to live lives characterised by discrimination and poverty. Nonetheless environmental, social and legislative changes do indicate that we are moving forward in the perception and treatment of disabled people. As a non-expert in old age, it does seem to me that there has been no similar revolution in the perception and treatment of old people and a second theme of this paper will be to ask why?

You will notice so far that I have talked about the perception and treatment of disabled and old people for the simple reason that there is an interconnection between the two; how we perceive a problem or group will have a great effect on how we treat it or them. For example, in the title of this conference the words care, management and complex needs figure large. In (post) modern societies all of us, from university professors to gerontologists to merchant bankers to doctors and nurses and on and on, have complex needs and without those needs being met,

none of us could function. Therefore the real question is why do we find it necessary to single out some groups and insist that their complex needs require care and management. This will be a third theme of this paper.

Historically both disabled and old people have been positioned as being in need of care and management. However, as I have already indicated and will discuss in more detail later, over the last thirty years disabled people ourselves have been extremely vociferous in rejection of such positioning? Old people, on the other hand, have not. The final theme of this paper will be to ask why? Underpinning this is the assumption that disabled people are right to refuse to allow themselves to be positioned in this way and that therefore, it would be right for elderly people to follow suit.

Independent living – definitions

Any outsider looking at current debates about disability would see the word independence figuring large. Politicians and policy makers though the law and policy documents promote the issue of independence for disabled people; professional organisations and professional practice has independence as one of the main goals for disabled people; and disabled people ourselves, when asked, reply that we want independence. The problem is however, that while the same word is being used, it is being used to describe three different things.

For disabled people, independent living is nothing more or less than a way of life. It is perhaps best summed up by the words of Adolf Ratzka, a disabled director of the Swedish Institute for Independent Living. He says that

Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect.

Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our everyday lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work in jobs that are in line with our education and abilities,

start families of our own. Just as everybody else, we need to be in charge of our lives, think and speak for ourselves.

Governments do not, however adopt such an all-embracing definition. By independence they simply mean independent from the State; not being a burden on the taxpayer or taking up scarce resources. Professionals too adopt a much narrower definition than disabled people. Their idea of independence focuses almost exclusively on self-care and the ability to do things for oneself; clean the house, cook a meal, do the shopping, dress oneself, wipe ones own bottom and so on. Thus, it is important to acknowledge that when we are talking about independence, we are not talking about the same thing.

What's more disabled people have organised themselves collectively through the 'Independent Living Movement' (ILM) and with the establishment of Centres for Independent Living (CILs) to promote our own view of independence and this has resulted in the recent setting up of the National Centre for Independent Living (NCIL). As far as I am aware there is no such debate going on in respect of independence and older people. In fact many of the organisations who purport to speak on behalf of older people seem to be actively promoting dependence rather than independence. And successive governments have actively forced their definition of independence on older people as they have progressively retreated from the provision of universal state pensions. The professions too have continued to operate within a self-care definition of independence often to meet the demands of NHS managers and doctors to get older people out of hospital as quickly as possible.

It may be argued of course, that the definition of independence adopted by disabled people is an inappropriate one as far as older people are concerned. To begin with, both the numbers of people with impairments and the extent of those impairments increase with old age. Additionally people's capacity's and capabilities deteriorate as they grow older making it more difficult for them to live independently. Finally, so the argument goes, many elderly people actively choose to give up the struggle for independence. These explanations fall within what might be called 'individual models' and end up blaming the victims themselves for what happens to them.

We might however posit what have become known as 'social model' explanations which focus on disabling and disempowering environment. So we might then see increasing dependence not as the inevitable consequence of the ageing process but as the product of dependency

creating, structures, services and assumptions. The introduction of markets into services for elderly people has resulted in the massive growth in the private residential care sector resulting in the ‘harvesting of the elderly for profit’ as one speaker at a similar conference to this one put it recently. Additionally, community services remain geared to the needs of the providers rather than the users of those services so it is hardly surprising that many older people go into homes instead. Finally, we disempower and disable with our assumptions; as one health care professional told me categorically when discussing what I might say in the paper “it is impossible for people with Alzheimers to live independently”.

The politics of the policy process

There is no doubt that most of the credit for the changes we have seen in the way disabled people are perceived and treated by society stems directly from our own self-organisation; in other words, the rise of the disability movement. Over the past thirty years, the numbers of disability organisations controlled and run by disabled people has risen rapidly at local, national and international levels. What’s more the big ideas around independent living, the social model of disability and civil rights has produced legislative and political change. We now have the Disability Discrimination and Direct Payments Acts as well as a network of CILs and other disability organisations up and down the country.

There is no comparable movement amongst older people in Britain. There are no similar radical organisations in this country to those that have grown up amongst older people in Australia and the United States. Further, there are no big ideas driving the policy process for older people in this country. They are still faced with the stark choice of managing their own lives independent of the State, its service structure and its professional carers or having their lives managed for them. Finally there has been little resistance to the inappropriate colonisation of much of their lives in the way that disabled people have rejected such a process over the last thirty years.

Economic considerations

It would be wrong, of course, to assume that it is only ideas that drive the policy making process. Economics also plays a key role and governments will usually adopt policy options which place the least strain on the public purse. There is no doubt that independent living and direct payments schemes have shown themselves to be cheaper than other state

provided options such as residential care or the more traditional domiciliary support services. This remains true whether costs are considered on an overall basis or by comparing individual cases by individual case. Not only that, but the quality of these services is also rated more highly, at least in terms of measured, user satisfaction. Government is now convinced that this is the way to develop services in the future and in recent guidance is seeking to extend independent living and direct payments schemes to other groups such as older people and people with learning difficulties.

As I have already indicated, I am not an expert in services for older people but my reading of the evidence on the comparative economics of domiciliary as opposed to residential care or hospital versus community based services is less clear cut: in some instances one is cheaper, and in others it is not. However, what we can say with a fair degree of certainty, is that most older people, just like most disabled people, prefer independence and living in the community to being incarcerated in hospital or residential home. Despite this preference since 1979 the numbers of old people in residential homes, particularly the private sector, has increased by more than 500%.

The two usual explanations for this staggering rise are firstly, that the numbers of dependent older people with complex needs have increased vastly throughout this period. Secondly, it is also argued that the stresses this places on other family members, particularly women, has resulted in families becoming less willing to care for elderly relatives. While there is obviously some truth in this, similar arguments could be made in respect of disabled people and yet here we have seen the process of decarceration continue rather than the headlong rush into incarceration which has been the fate of many elderly people. One thing that has been learned as far as disabled people are concerned is that degree and extent of impairment is relatively unimportant in determining whether disabled people end up in care or not.

If this is the case, we need to ask why we have not seen similar developments in services for older people to those we have seen for disabled adults?

The role of voluntary organisations

One powerful reason for this may be the lack of voice that elderly people have about their position and role in Britain. It is clear from the recent offerings by all the parties at the General Election that none of them saw

older people (or disabled people for that matter) as a major priority and older people were unable to properly articulate their demands to prospective politicians. However it could be argued that the national voice of older people is represented by several large and powerful national voluntary organisations whose role it is to articulate their demands.

But this is not necessarily the case as the recent experience of disabled people demonstrates. One of the first things the disability movement did when it came into being was to challenge the right of traditional disability organisations to represent us and to speak for us. Over the next few years the schism between organisations of disabled people and those for disabled was absolutely central to the emerging disability politics. And it should be made absolutely clear that those big ideas I mentioned earlier all emerged from organisations of disabled people and not the traditional disability organisations who were either neutral in respect of them or who actively opposed them in some cases. Now, of course, they espouse them as if they are their own.

We have not seen a similar schism emerge in the development of organisations for older people. Apart from the National Pensioners Federation which is controlled by older people, the other age related voluntary organisations all are more accurately called organisations for older people rather than organisations of them. Thus they lack the authentic voice of older people and they can be criticised on similar grounds to those organisations for the disabled: that is they are professionally dominated, they are hand in glove with government, they are only interested in promoting their own organisation and so on.

In seeking to explain this lack of collective self empowerment amongst older people, there are a number of possible explanations. It could be argued that the voluntary sector is doing such a good job representing the interests of older people that there is no need for an alternative movement to develop. It could also be argued that as people grow older they 'disengage' from the political process. Whatever the explanation, it remains true that older people do not get the kinds of services they have a right to expect and that there is no powerful, political voice making their case to Government in the way that the disability movement is making the views of disabled people known to anyone who will listen.

Sheltered housing and residential care

In the process of incarcerating more and more older people with complex needs, the main mechanisms for accomplishing this have been sheltered housing and residential care. In the case of disabled people we have actively rejected both of these as solutions to our desires for an independent life, as defined by us ourselves. To put a personal spin on this, during my own 40 year career as a disabled person there have been occasions when I have feared that such a solution might be imposed on me but in all of that time I have never seen sheltered or residential accommodation that I would enter as a free choice.

As the years go by, I wonder whether circumstances will ever force me to consider sheltered housing or residential care for old people but again, in my personal and professional experience of such provision, I have again never seen any such provision that I would enter willingly. This leads to an inevitable question: if I don't believe such accommodation is good enough for me, why should I believe it is good enough for anyone else?

This personal question leads to a more general one: do we as a society lack both the imagination and the will to design an appropriate range of community based services that will allow older people to live out their lives in the ways that they choose or will we continue to force solutions on them that are more convenient and perhaps more cost effective for the rest of us?

Conclusions

In this talk today I have tried to draw some parallels in the experiences of disabled and older people have suggested that disabled people have been actively rejecting the notion that we need management and care to the point that we have developed a very clear vision not of what we need, but as you will see from the following quote, what we demand.

“We demand social welfare systems that include personal assistance services that are consumer controlled and which allow various models of independent living for disabled people, regardless of their disability and income. We demand social welfare legislation which recognises these services as basic civil rights and which provide necessary appeal procedures”

(European Network on Independent Living)

Older people do not seem to be making such demands at present and I post one final questions: do we need to wait until they do or can we design and provide the kinds of services they have a right to expect?

After all, we all get older every day and we may only be designing and building an independent future for ourselves.