Community Care Providers Scotland Conference

'MAKING SENSE OF COMMUNITY CARE'

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Recent Initiatives: A service user's perspective; or, Farewell to Welfare - The perspective of an ungrateful bastard.

Introduction:

I stand before you, as accused - an ungrateful bastard.

I am supposed to be here discussing a service user's perspective of recent initiatives in community care: initiatives you have been discussing this morning from your perspective as providers.

But, who am I to be standing here as the voice of the 'user'? Who has given me that right? To whom am I accountable:

♦ the old lady with senile dementia in the Dumfries nursing home;
♦ the young man with mental health problems wandering the streets of Aberdeen;
♦ the disabled mother of two toddlers, imprisoned in her Edinburgh high rise flat, waiting for her husband to come home to help her to the toilet?

Well, actually, none of these - because they have not asked me to speak on their behalf. They do not even know me. I doubt if they've even heard of the new policy initiatives in community care you are talking about at this conference. "Community what?" they may even ask. Yet, what you are discussing here today may well affect them more than it affects either you or I.

I have been invited here because, in some high quarter, I have been noted to have a big mouth; and I use it to expound the thinking of a fairly large group of physically impaired and - on the whole - fairly articulate people. We are generally referred to as 'the disability movement', or, by reference to the desired outcome of the movement, as the 'independent living movement'.

The movement has been termed by some as 'elitist' and 'unrepresentative' of the commoner - the 'punter', as we say in Glasgow. We have even been called a stroppy bunch of 'ungrateful bastards' (Oliver, 1994).

Indeed, a number of professionals have questioned the validity of the disability movement as a representative voice of disabled people. The fact is, Britain is what is called a representative democracy, in which a variety of interest groups are accorded legitimacy to speak on behalf of whole constituencies. But such a system is, *ipso facto,* always considered less than perfect, as Vic Finkelstein a major protagonist of the movement points out:

> "**My position was that in a representative democracy**

> **where people organise and present their views, you take**
> **those views to represent the group they say they are**
> **representing until other organisations emerge to**
> **challenge them. That's what democracy is about. Inasmuch**
> **as there is no other reflection of their views, these are**
> **their views. The fact that it's a minority membership is true,**
> **but the question is 'Who speaks for the majority?' I once**
> **gave a talk to a medical disability group and they raised**
> **this issue. They said, 'These views you're putting forward**
> **are interesting, but they only represent a minority of disabled**
> **people.' So I said, 'Who represents the majority? You?' Of**
> **course, they just became embarrassed, because if it isn't us,**
> **it's them, the doctors." (Campbell and Oliver, 1996)**

Over the last fifty years, or so, disabled people, from various backgrounds and with a panoply of experience, have come together to form the movement. We have all suffered social and economic oppression at the hands of the state; its institutions and prevailing attitudes. We have looked. We have discussed. We have researched and analysed. And we have come up with some rather radical conclusions and solutions.

The failure of welfare

You see, as my fellow comrades in the disability movement have said before me, we believe the British welfare system has failed disabled people. For example, my ex-boss, Ken Davis (1994) once wrote:

> **"It has failed to bring us into the social mainstream,**
> **failed to bring us equality of opportunity, but it has been**
> **gloriously successful in spawning golden career**
> **opportunities for hordes of 'welfare professionals' doing**
> **good works in 'looking after' us and, in the process, of**
> **keeping us out of sight and mind. For us, the political**
> **intentions underlying welfare are revealed in a system**
> **designed to limit social change and to protect and**
> **enhance able-bodied privilege." (Davis 1994)**

Davis (1994) goes on by saying:

> **"The upshot of 'community care' is that we are to be kept**
> **in the role of eternal children, where grown up service**
> **(Commissioners) who know what's best, purchase services**
> **on our behalf. And already the new marketeers are beginning**
> **to win contracts from statutory purchasers to care for our**
> **needs, all working in competition and all providing things**
> **that disabled people never asked for." (Davis, 1994)**

This assertion can be validated by academic research. For example research has found that disabled people are not involved in any meaningful way in the community care consultation

process. Our needs are not being met by social work services. Local authorities also refuse to take their legal responsibilities seriously, even when there are court orders against them. (Ellis 1993, Bewley and Glendenning 1993, Keep and Clarkson 1993) No wonder only a tiny number of disabled people want to use community care services. (Blaxter, 1976, Lakey, 1993)

Professor Michael Oliver, of Greenwich University, argued all of this at a conference of the Association of Directors of Social Services in 1994. He paraphrased the response of one chairman of social services to his argument:

> **"It's all very well for you - you are only a small stroppy
> minority of ungrateful bastards. Disabled people in
> Wolverhampton like the home help service, they like
> going to day centres, they like the residential care we
> provide; and it's time you ungrateful bastards shut up."
> (Oliver 1994).**

Well, this ungrateful bastard is here and I shall continue to argue in the same vein as my friends and colleagues in the movement.

We will not shut up until such bigoted paternalism is expunged from welfare provision.

In fact, we will not shut up until

♦ today's needs-based system of 'welfare' is superseded by tomorrow's rights based system of 'citizenship' '
♦ today's 'dependency creating care' provision is succeeded by tomorrow's provision of 'emancipatory services'
♦ today's Hobson's choice of care is supplanted by real choice and control by the individual

We will not shut up until all such champion concepts are securely submerged into the policy, practice and professional psyches of an empowering system of community support, the objective of which is to enhance and sustain the full and equal citizenship of everyone in society.

We will not shut up until we can safely say, "Farewell to welfare!"

Now, there is a danger when disabled people say things like that, some professionals working in the system understandably get a bit defensive and feel we are getting at them, personally. That is not so. I know we have plenty allies and friends among professionals in the welfare system, who are just as critical of it, and as frustrated by it, as we are. These are 'the good guys'.   I am reminded of Shakespeare, no - not William, but Tom of Newcastle University, and a protagonist in the Independent Living Movement. He writes:

> **"Our real enemy is not individuals, but the system which
> divides us, which creates our disability, which makes it
> possible for others to profit from our exclusion: it's
> convenient and easy to highlight people, but the focus
> of our rage and our action should be the structures."
> (Shakespeare, 1993)**

The disability movement is quite aware that it must work with professionals in the system, cultivating them and converting even more of them to our way of thinking, before any real **'revolution'**, in welfare can take place. I use the term **'revolution'** quite deliberately, to distinguish my objectives from that of government, which is merely to maintain the status quo of welfare through their **'pseudo-reforms'** and **so-called 'initiatives'**.

From welfare to citizenship

So how have these recent initiatives in community care, such as the Regulation of Care Act, Joint Futures Group, Best Value, The Care Development Group, Direct Payments - to mention a few - matched up to these champion concepts of the independent living movement? How far have they met our goal of changing a 'needs' based welfare system of 'care' provision into a 'rights' based system of 'emancipatory service' provision, with the objective of promoting this concept of 'citizenship'? In fact, how far have they even matched up, simply to the wider picture of social policy in Britain, like Social Inclusion, the Disability Discrimination Act and the Human Rights Act?

Time does not allow me to go through them all. Instead I shall describe something of what some might say was the **'utopia'** of the independent living movement and let you estimate how far the welfare state has to travel. But please remember it was only just under 200 years ago (a mere tick in the time of history) that William Wilberforce was told that his dream of freedom for slaves in the colonies was **'utopia'**.

Before I go on to describe our vision, let me take you to South Africa in the year 1964. Nelson Mandela is making his speech before the court, which will shortly sentence him to a life sentence on Robben Island. He is saying:

> **"….. Africans want to be paid a living wage. Africans want to perform work which they are capable of doing and not work which the Government declares them to be capable of. ……. Africans want to be part of the general population and not confined to living in their own ghettos. African men want their wives and children to live with them where they work, and not be forced into an unnatural existence in men's hostels. …… Africans want to be allowed out after eleven o'clock at night and not confined to their rooms like little children. Africans want to be allowed to travel in their own country and to seek work where they want to and not where the Labour Bureau tells them to. Africans want a just share in the whole of South Africa. They want security and a stake in society. Above all, we want equal political rights, because without them *OUR DISABILITIES* will be permanent." (emphasis added) (Mandela, 1978)**

Mandela used the term 'disability' to describe the oppression of black people in South Africa. According to the state, the situation of black people was due to the colour of their skin. According to Mandela, black people's oppressed situation was caused by the state's negative

reaction to the colour of their skin; and such reactions caused them to have disabilities; disabilities which restricted their life opportunities, their freedom.

Similarly, it is not my cerebral palsy, which causes my disabled status in Scotland, but society's negative reaction to myself with cerebral palsy.

What happened to black people in South Africa happened to disabled people in Britain. In each country, the state set up different systems of social support - separate housing; separate transport; separate education; separate employment. In South Africa it was called Apartheid. In Britain, it was called 'Social Welfare'.

The meaning of welfare

But what does the word 'welfare' mean?[1]

Certain writers distinguish between the word 'wellbeing' and the word 'welfare', arguing the former has greater propensity to quality of life indicators. (Osborne, 1992).

However, 'welfare' comes from the adjective' well' and the verb 'fare'. 'Fare, derives from the Old English word 'faran' and has two basic but linked meanings: 'to travel', to go' (as in 'seafaring', or 'wayfaring'); and 'to happen', 'to be in a state'. The two meanings are linked in Old English e.g. 'I fare butan bearnum' means 'I am without children': 'I am in a state of childlessness'. Literally, 'I go/exist without children'. So 'go' and 'exist', or 'be' are linked. The state in which we GO through life is how we ARE.

In German they say "Wie gehts?" as a greeting: in France, they say 'Ca va?' and, according to Stanley Baxter's "Parli-amo-Glesca", some might drunkenly say 'Hoy, Jimmy, how's it gawin'?' All mean, 'How goes it?' 'How are you'. Life, after all is a journey!

'Welfare' and 'wellbeing' were originally synonyms, although, since the 20th century, the former has had political and social overtones - as in, 'the welfare state'. As with 'apartheid', which just means 'separate development', the neutral term 'welfare' has now become overridden with negative connotations. However, the cause of such negativity can be traced back to the immediate onset of the policies, which promoted the concept. For example, it was Lloyd George himself who quite openly stated that, **"by concealing the real causes of poverty, his first national insurance scheme was the capitalist way to avoid even bigger changes in the organisation of society. Their political task was to protect the prevailing status quo, and welfare was the tool." (Davis, 1994)**

Before the Second World War charity was the main source of basic welfare for the poor, old and disabled members of society. The welfare state, created after the war, was merely the nationalisation of charity. As with the nationalisation of health, which incorporated the entrepreneurship of doctors, so the new state welfare system relied on the values, objectives and organisation of charitable bodies. The professionals and bureaucrats of the new state welfare

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[1] For assistance with my understanding the etymology of 'welfare', I am very grateful to Graham D. Caie, Professor of English Language, Department of English Language, School of English and Scottish Language and Literature, University of Glasgow

system perpetuated the same stigmatisation and regimentation of the 'needy', established by charities.

As an aside, it has always been a grave disappointment to me that so many voluntary bodies have chosen to join with the state welfare system in the provision of segregated and disempowering services, rather than campaigning to affect social change by making civil and community provision totally inclusive. Not only that, but now that they are rich and powerful partners within state welfare, many are seen to be actively working against the empowerment and autonomy of those they say they help.

The meaning of need

In his book, 'The needs of strangers', Michael Ignatieff (1984) considers what is meant by needs. His main interest is in how society has translated such considerations into the development of the Welfare State. In particular, he looks at how such a state institution has buffered the needy stranger from the relatively rich taxpayers.

Ignatieff (1984) points out that the Welfare State is not generous, but it does set out to satisfy a broad range of needs; food, shelter, health. But what about our 'social' needs? He asks, is there a difference between our needs of basic survival and our needs to develop our full potential, our 'self-actualisation'; and what about our need to flourish?

He goes on to discuss the political arguments over the language of needs versus the language of rights; the debate between personal freedom and the collective good.   This, he reflects, is the contradiction at the heart of the welfare state. To simplify, with reference to the House of Lords decision over the Gloucestershire case - local authorities may have to have a system to meet need among disabled people, but that system does not have to meet the need of a particular disabled individual

This legalistic view sees welfare as 'blanket provision'. 'Blanket' in the sense that it is uniform and basic. 'Blanket', not used as a cover to warm and nurture our full potential, but used as a net to catch people as they fall from the giddy heights of individual self-reliance. However, as with any net there are holes in this blanket. These holes are actively torn in the blanket to allow those who are not seen by politicians and professionals as needy or as deserving, as others, to fall through.

Ignatieff (1984) sees welfare as barely meeting man's basic needs as a 'natural' being, food, shelter, warmth, but doing nothing to meet his 'social'' needs as a member of a family, or citizen of the state. He argues, treat people as individuals, thereby giving each their place and respecting their distinct characteristics; and you treat people unequally.   Treat people as members of the same genre, without recognising their individual differences and unique place in the family, or society at large; you, thereby, treat them equally.

However, treating everyone the same, often ends in treating them like things. As an example of this many disabled people feel nurses and residential care workers, generally, make such poor personal assistants (support workers) because their training and work experience has lead them to give 'equal' treatment to, and take 'equal' responsibility for, all in their care. Thereby, they are perceived as treating people as objects, rather than as social beings.

When, over forty years ago, Sweden began decanting disabled people from institutions and developing their community care support systems not only was this problem recognised, but so was another -

> **"In the systems of nursing and integration the disabled**
> **person has to play several different roles. In the**
> **customary institution he is a passive receiver of help**
> **and assistance.   When living freely and independently,**
> **the disabled person - like all others - has to ask for service.**
> **Our investigations show that many disabled people starting**
> **their integrated lives find it difficult to exchange the passive**
> **role of receiver for the active one of ordering service.   We**
> **found that nurses and service assistants have the same**
> **problem although the direction is reversed. A well-educated**
> **and well-trained nurse who is familiar with her role of**
> **thinking and acting for the disabled (person)[2] will have**
> **considerable psychological trouble when she has to take**
> **her place as a service assistant to the disabled (person).**
> **If we are unable to teach and train the disabled (person) as**
> **well as the service staff for these new roles we will**
> **lose the possibility of real integration. This training is**
> **therefore a very important part of the rehabilitation**
> **process." (Brattgaard, in Boswell, et al, 1972, p. 8.)**

As can be seen from this extract, transferring power from the professional to the individual can be difficult for both parties. This is because, traditionally, 'need' has been analysed and administered to by those, whose powers are invested in them by the state, i.e. professionals. They define need. They even determine how need is defined. They determine whose need should be met and by how much. Conversely, they determine whose need is not to be met. They also determine the manner in which need should be met, as well as the manner in which it should be received. Finally, this power, which is given to professionals, is conditional on them maintaining the status quo of society at large. (McNight, 1977)

Even within New Labour's new model of welfare, called 'Social Inclusion', the power still remains with the status quo. It proposes a solution to which we were not party and from which only a few of us may benefit. In addition, the lack of joined-up policy making makes a mockery of its overall-all policy objectives. For example, perhaps the New Deal may assist some disabled people into the labour market, but only those who can adapt themselves to the status quo of the market. The New Deal does nothing to alter the structure of the labour market to accommodate severely disabled people. In the meantime, the welfare benefits of those very people who are discriminated against by such structures are slashed by the draconian Utilitarianism of New Labour Social Security Policies.

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[2] (The noun `person' has been added after the adjective `disabled' in this quote to avoid discriminatory language.   Undoubtedly, the writer also has difficulty with sexism, as he assumes the carer will be female.)

Manual handling

Another prime example of this lack of joined-up policy decision-making is the new Manual Handling Operations Regulations and their interpretation. How do they meet Tony's Social Inclusion objectives?

Even the title is discriminatory and dehumanising. Packages are manually handled not people. The terminology of 'manual handling' is a worrying extension of the exercise of power by professionals, which is clearly evidenced in their language. Their use of depersonalisation in their reference to clients - 'amputees', 'the blind', 'wheelchairs', 'beds', etc. - is a major force in client / patient control and management.

When training personal assistants at the Centre for Independent Living in Glasgow, we refer to such activities covered by these Regulations as 'Moving and Assisting'. Although this is a much more simple title, I much prefer the more accurate title of 'The ergonomics of physical assistance'.

Language and titles apart, the lack of meaningful involvement by users in the development of these regulations has allowed the professionals to run riot in developing inappropriate measures of risk management. Such over-restrictive interpretation of health and safety legislation - such as blanket 'no-lifting' policies - undermines disabled people's health and independence, never mind our human and civil liberties.

The problem from the service provider's point of view includes -

- ♦ high incidence of back injuries
- ♦ fear of liability
- ♦ lack of training

From the disabled adults and children's points of view restrictive lifting policies mean:

- ♦ constrained lifestyles and institutionalisation
- ♦ more pain and discomfort
- ♦ dramatic loss of independence and dignity
- ♦ loss of mobility and weight-bearing abilities
- ♦ extra costs for equipment
- ♦ dangerous 'coping' behaviour such as struggling to maintain low body weight

Total avoidance of risk is impossible, what is required is appropriate management of risk, involving the disabled person's wishes and decisions. The Regulations do not rule out 'manual' lifting, but research shows that professionals are avoiding 'manual' handling altogether and using the Regulations as a reason. It should be pointed out, however, that such 'no-lifting' policies are likely to be unlawful under the Human Rights Act 1998.

The Human Rights Act as it relates to the freedom from torture and inhuman or degrading treatment or punishment; the right to dignity; the right to choose or refuse who touches you, or sees your naked body - all have profound implications on the 'carer - cared for' relationship. For

example, Jane Campbell, Co-Director of the National Centre for Independent Living, in a paper about the government's 'Quality Agenda' has drawn attention to the total absence therein of a civil and human rights perspective. She states:

> **'Currently disabled people can be in danger from covert**
> **forms of abuse from paid and unpaid carers because**
> **their Impairment requires human assistance to survive.**
> **If no alternative provision is available other than the person**
> **who is abusing, then this may be considered a denial**
> **of human/civil rights. (Campbell, 2000)**

Campbell (2000) cites the case of a woman in 1998 who complained to her local authority, she felt unsafe in the presence of her home help and did not want her to bath her. The authority refused to change the home help, telling her not to be so fussy. The woman was later found badly beaten by the home help.

The right to choose who should help you with intimate tasks should be accepted by everyone, even if it does cause administrative headaches with service providers.

We need to balance risks and rights. We need to reinterpret regulations to ensure those policies and practices - not just on moving and assisting, but on the administration of medicine and invasive care - are based on the respect, dignity and rights of disabled people. We must develop adequate information, training and resources for all those involved. Above all, we must get together - government, service providers, regulators, professional bodies and disabled people - to open a dialogue and resolve our differences. (NCIL, 2001)

Emancipatory services

This situation exemplifies the need to look at welfare in the light of civil liberties. As Mandela (1978) says, without equal political rights, without the means to participate equally with those who presently oppress us, black people and impaired people - whether physically, sensory or mentally - will be permanently disabled within society

This 'social model' of disability, which was developed by disabled people in the 1960's, was heavily influenced by the struggle for civil rights among people from differing ethnic minorities. And it is this 'social model' which has subsequently influenced the design of emancipatory services within the independent living movement. To my own way of thinking, the main pillars of such emancipatory services are -

*	citizenship	*	self-assessment
*	self management	*	participation

Citizenship

A system based on the pejorative concepts such as 'need', and 'vulnerability' denies users of their right to citizenship and self-determination. As Ignatieff says:

> **The language of citizenship is not properly about**
> **compassion at all, since compassion is a private virtue,**
> **which cannot be legislated or enforced. The practice**
> **of citizenship is about ensuring everyone the**
> **entitlements necessary to the exercise of their liberty.**
> **As a political question, welfare is about rights, not caring,**
> **and the history of citizenship has been the struggle to**
> **make freedom real, not tie us all in the leading strings**
> **of therapeutic good intentions'. (Ignatieff, 1989)**

The discourse of 'Citizenship' has come in and out of fashion as British society lurched from one crisis to another as one group or another demanded more political or social freedom. 'Citizenship' is basically the relationship between individuals and their societies.

T. H. Marshall started present day discussion around 'citizenship' in the 1950's. (Marshall 1952) He postulated that citizenship could be achieved through securing rights. These rights he divided into political, social and civil. Later, Lister (1991) took the idea of citizenship not just to look at the political and social integration of the majority into society, but as a measurement of the exclusion of certain groups, e.g. poor people.

In terms of disabled and older people, it has been argued that many of our rights to citizenship have been denied by the welfare state, (Oliver, 1984, Barnes 1991, Zarb and Oliver, 1993).

Time does not permit me to list the ways in which disabled people have been excluded from society, in education, employment, housing, leisure and recreation. I can of course refer you to the excellent work by Colin Barnes, "Disabled people in Britain and discrimination" (Barnes, 1991) and Michael Oliver's recent book "Understanding disability: from theory to practice" (Oliver 1996).

Barnes (1991) in particular was arguing for anti-discrimination legislation. The Government were finally shamed into bringing forward the Disability Discrimination Bill in 1995 which gave us certain limited rights in the areas of employment, getting goods and services and buying or renting land or property. Access to education and public transport was to be improved; and a National Disability Council established. Very little evidence is available concerning the impact of the Disability Discrimination Act on the quality of life of disabled people. Some are saying it is toothless, whilst others are relying more on the Human Rights Act (Campbell and Oliver, 1996, Campbell, 2000). As it is, there is little or no case law to show disabled people have gained any great benefit from these pieces of legislation.

Drewett (1999) has even argued that the 'needs-rights' dichotomy is over-played and, in fact, there is considerable over-lap between the two. She goes on to argue that a 'rights' based service will only lead to greater budgetary constraints. What Drewett fails to look at is the power relationship between professional and client within the two systems. Within a rights based system, the imbalance, which exists within the needs based system, is somewhat rectified and stigmatisation greatly reduced (Jones, 1994).

The Gloucestershire decision in the House of Lords was three to two, a very close decision. That decision has led to a situation in which the satisfaction of an individual's need is dependent on

the political priorities of people in power who do not understand nor want to understand the social oppression they exert on disempowered members of their community. Therefore, the continuation of a needs based service will, in my opinion, deny many their basic human rights, as laid out by the United Nations, the European Union and now the British legal system.

The only flicker of hope I see in this sea of new legislation is the Community Care (Direct Payments) Act. This is an act which came from the disability movement's struggle to give ourselves the freedom to choose how and where to live; to choose who should provide support and when that support should be given. The freedom to be in charge of your own life, is the greatest form of emancipation you can achieve.

The disability movement conceived this legislation. We nurtured it through the womb of parliament and laboured over its enactment. It is our baby. Yet, as Witcher et al (2000) have shown, only 13 out of the 36 local authorities have implemented this legislation; and even then most have only small scale pilots. They seem to be too concerned to maintain their own - what is for many - inappropriate services, that they refuse to give people a choice between receiving a direct service, or a direct payment.

But for many disabled people, like Jack, in Jenny Morris' book 'Community care or Independent living?' the freedom direct payments give to people can be overwhelming:

> **"I'm a husband, a father and a breadwinner. And ten years ago I was in an institution where I couldn't even decide when to go to the toilet … you know, you can't really understand it if you haven't done it … your whole life changes." (Morris, 1993)**

Hopefully, the introduction next year of making direct payment mandatory, will force local authorities to drag their Neanderthal knuckles along the road to disabled people's emancipation.

However, the promotion and maintenance of citizenship is being actively undermined by the government's benefits and community care charging policies. These two policies act as a painful pincer movement squeezing disabled people into a state of constant poverty whether or not we are in the labour market. If we are outside the labour market the government's Utilitarianism keeps welfare benefits at meagre sustenance levels. If we are in the labour market we are hit by massive discriminatory local disability taxes in the form of community care charges. So, whether in or out of the labour market, compared with our able-bodied citizens, we are financially penalised in our efforts to execute our rights and duties as citizens of the state.

Don't we pay our Community Charges, just as anyone else? Don't these taxes pay for council services, including social work? So why should one service be free at the point of delivery and not another? Disabled people throughout Europe are demanding that personal support services, what Sutherland calls 'personal care' should be - like health - free at the point of delivery.

Self Assessment and Self Management

Ignatieff (1984) ponders the question, do we, as individuals, know what we truly need? Would it not be best to leave it to others to assess our needs? Ignatieff argues that the claim of need

highlights the relationship between the powerful and powerless human. He argues a claim of need should be taken on trust, because without trust the world would be a murderous and pitiless place. Therefore, the powerful, e.g. politicians and professionals, should accept the value of self-defining need, for, without trust, there is mere oppression,

There is an interesting story by Dick Leaman (1996), who was an activist within the movement, which illustrates this point. A disabled woman phoned up her council because she wanted her bedroom door to open the other way to give her more space for her wheelchair. The council could not help her because there was a waiting list for O.T. assessments. The lady did not need an O.T.. She needed a joiner to re-hang her door. The denial of trust in the lady's self-assessment resulted in her continued impoverished quality of lifestyle.

In Shakespeare's play "King Lear", there is an interesting dialogue, which takes place on the heath, between Lear and his daughters. As a king Lear could demand the fulfilment of every whim or desire, but now as a pauper he is made to justify his plea for help.

All his life he had been addressed in the supplicating language of need from his subjects. Now, as a pauper, he has to use the same language and reason for his need. As a king he had no claim that needed an argument; as a poor man he is forced to give reasons and account for himself.

Lear cries:

> **"0, reason not the need!   Our basest beggars**
> **Are in the poorest thing superfluous.**
> **Allow not nature more than nature needs.**
> **Man's life is cheap as beast's. Thou art a lady,**
> **If only to go warm were gorgeous,**
> **Why, nature needs not what thou gorgeous wear'st,**
> **Which scarcely keeps thee warm. But for true need -**
> **You heavens, give me that patience, patience I need. "**

I know how he feels. All recipients of today's welfare could do with more patience, but why should he beg like this? He is asking his daughters for help. Should he reason with his daughters?   Have the daughters not got an obligation to their father?

What Lear is asking for is a retinue of knights - not something all human beings need.   Yet, as Lear says, if we were all judged by the standards of our natural need, no one would have their social needs satisfied. We would be like animals.

The social world, he argues, is a place of differences, where each person's needs depends on their rank, position and history.   Lear also argues as a man. His rich daughters must have thought they needed gorgeous flimsy clothing, which would not keep them warm. Presumably, they had other means of keeping themselves warm, like a nice big castle, with great big fires in the hall and bedrooms and lots of servants to keep them burning bright. To question anyone's need, Lear says, is to presume they lack the capacity to know their own minds.

His daughters had just done that -

> **0 sir, you are old**
> **Nature in you stands on the very verge**
> **Of her confine.   You should be ruled and led**
> **By some discretion that discerns your state**
> **Better than you yourself**

How often have you heard something like that said to old people or disabled people by those who care for them? "We know what's best for you!"

Lear's daughters saw his cry of need as a cry for power. To give Lear his knights would be to give him power. Similarly, to give those on welfare adequate resources would be to give them power. To give power to the powerless - is this not the stuff of revolution; are we not in danger of overthrowing the establishment?   Ignatieff (1984) argues this depends on whether you look upon `the needy' in terms of an equal fellow, who should have the same opportunities to exercise power over their own lives as you; or as lesser people, who should have less opportunity and remain in a state of dependency upon your power.

Some professionals say that their clients do not know what they really need.   There must be some objectivity - but objectivity never exists.   Assessment of needs happens within a set of political parameters and within the confinements of finite resources - both determined by powerful people, led by their prejudices and alliances.

Ignatieff states -

> **".... Human beings must be trusted to know themselves,**
> **however imperfect we admit self-knowledge to be, for**
> **without trust, there is no limit to oppression.   If the**
> **powerful do not trust the reasons of the poor, these**
> **reasons will never be reason enough. A rich man never**
> **lacks for arguments to deny the poor his charity. (Ignatieff,**
> **1984, p. 34)**

At a conference in 1995, John Evans, Chair of the Independent Living Committee of the British Council of Disabled People, said:

> **'There ought to be no compromise regarding self**
> **assessment; it is fundamental to the empowerment of**
> **disabled people. It is critical in terms of the**
> **assessment process that self assessment is the starting**
> **point in enabling disabled people to determine their**
> **own lifestyles.' (Barnes, McCarthy and Comerford, 1995)**

Self-assessment and self-management, or SASM, if you want the jargon, depend on people making informed choices about their needs (Priestley, 1999). However, such choices, if they are to be meaningful and effective, must be based on a conscious awareness of what is involved and what are the consequences. Clearly, this is no mean feat. Many disabled people have been socialised into a feeling of disempowerment and dependency. They may lack the knowledge and confidence to make a choice.   Indeed if you were to ask them a straightforward question, "What

do you need?" research has found they are more likely to underestimate their requirements (Kestenbaum, 1993)

Support for self-assessment and self-management can include meeting other disabled people and learning from their experience; peer advocacy; and training. Peer involvement in support to self-assessment and self-management provides positive role models for people and develops their sense of empowerment, identity and social inclusion.

Priestley (1999) also points out that self-management means that many of the 'difficult decisions' about rationing resources are devolved to the 'user'. They may have to choose between organising assistance to write a letter, or do the laundry. The importance of one over the other may vary from situation to situation. The value of self-management is that the 'user' can take that decision. Macfarlane (1996) also points out the disjointed nature of the care system, whereby nurses catheterise, but do not empty commodes, home helps empty commodes, but do no domestic duties, like cleaning the bathroom. Self-management would provide a far more qualitative service provision, because it would allow the individual manager to draw up the job description to meet his or her own care needs.

The NHS and Community Care Act policy guidance makes it clear that self-assessment and self-management should be integral to the care plan. Unfortunately, I feel this has not happened in any substantive way. The new Care Standards report mentions 'choice', dignity' and 'empowerment', among other admirable concepts. Peer advocacy is even mentioned, but it is difficult to see any kind of compulsion being exercised in many of these initiatives and very few resources.

Yes, it will be up to inspectors to implement the standards, but who is inspecting the inspectors? I strongly believe there is a need for 'lay' inspectors; a disabled or older person from the local community accompanying inspectors on their visits to homes. Prisoners have them, so why not care home residents? These care home inspectors are now part of a national commission, which was supposed to comprise a majority of 'users' and carers. I now understand, the Scottish Executive has watered down the involvement of 'users' in the Commission, following the recent fiasco of the SQA - a move I greatly regret.

Participation

This brings me to the final pillar of my emancipatory services - participation.

As Alinsky says in his book 'Rules for radicals':

> **'We learn when we respect the dignity of people, that they can not be denied the elementary right to participate fully in the solutions to their own problems. Self-respect arises only out of people who play an active role in solving their own crisis and who are not helpless, passive, puppet-like recipients of private or public services. To give people help, while denying them a significant part of the action, contributes nothing to the development of the individual. In the deepest sense, it is not giving, but taking - taking**

> **their dignity.   Denial of opportunity for participation is the**
> **denial of human dignity and democracy. It will not work.'**
> **(Alinsky 1971)**

The introduction of self-assessment and self-management into case management has shown the value and effectiveness of disabled people being involved in the operation of our own individual support systems. The independent living movement has also shown that where disabled people are involved in the planning and running of overall support systems, then those systems become more empowering and emancipatory.

A system of emancipatory support services, which promotes disabled people's citizenship, empowers us to be

♦   individual consumers, exercising choice through self-assessment and self-management;
♦   peer advocates, providing peer support and positive role modelling;
♦   representatives, contributing to the strategic development and evaluation of service design:
♦   participative citizens, seeking to identify and remove disabling barriers in their communities:
♦   and political actors, within a wider movement for social change.

This multifunctional role enables the quality assurance agenda of service provision not only to be more meaningful, but also to be effective and achieve best value. It will achieve best value, because the service will reflect the expressed need of disabled people within a framework of our conscious awareness of political and resource constraints. It will also achieve best value because the expectations of service recipients will be greatly higher. As one client of a user-led provider organisation said:

> **"I don't mind being let down by the professionals ….. they**
> **will fail you because it's a job at the end of the day. I do**
> **feel a greater depth of disappointment with the DCIL,**
> **because I expect them to have the gut feeling that I have**
> **when I deal with disability issues. And if that doesn't come**
> **through then I am disappointed (Hugh)" (Priestley, 1999)**

The recent exercise in creating care standards for both the single care home and the new regulation of care legislation did try to involve users in its various committees. This followed the Scottish Executive's initiative to involve 'users' and 'carers' in the development of community care policy. I was one of the 'user' representatives on three of the committees.

Back in 1996 the Social Work Services Inspectorate commissioned Dougie Herd and Kirsten Stalker to write a report describing good practice in involving disabled people in service planning purchasing and providing. (Herd and Stalker, 1996) Herd and Stalker (1996) made many recommendations to facilitate user involvement in the planning and implementation of services. Although some dubious market research was carried out among users, not all of Herd and Stalker's recommendations were implemented. I also feel some of those user representatives who were involved were gravely disadvantaged for the following reasons:

♦   In the main, there were no pre-agenda meetings for users to get their heads around complicated issues and thrash out differences of opinion; or to work up issues to be tabled at

the main meeting. So users showed up as having a disunited front, or not participative, or lacking in awareness

♦ Papers were tabled on the day, thus disadvantaging those with sight and intellectual impairments

♦ Other representatives around the table had large and well-resourced organisations behind them to feed them data and argument. Most user representatives only had their own limited experience

♦ Other representatives were well versed in committee skills, the formation of arguments and counter-arguments. For some user representatives, all this was new territory. Some had advocates, others did not, and I felt the quality of some of those who had was questionable

Earlier this year there was the first national conference of service users in Scotland - a gathering from all over the Nation of different user groups, small groups in the main, to talk about how they overcame the barriers in the way of achieving some goal. The agenda was user-led. The organisation was user-led. The methodology was user-led. The day was user-led. It might have taken much longer to organise. It might have been more expensive. But what it achieved in terms of user morale, user commitment and user benefit was immeasurable. What was missing was an effective link to policy development but that is now under consideration.

What policy makers and service providers need to do is to stop leading service users by the nose into Board rooms and consultation processes; demanding that we join in their game and play to their rules, at times and in a manner suitable only to them. Instead, I would suggest they follow behind us - at a respectful distance - and listen to our agenda and at times and places suitable to us; and in a manner, or methodology, convenient to us.

Consultation is not an event, it is a process - a process which needs thought, money and other human and material resources; a process which needs commitment from everybody from the chief executive downwards.

Consultation is a meaningless and wasteful exercise, unless there is commitment to treat us as equals - equals with a valid and knowledgeable viewpoint; equals with the same commitment to best value and high standards of service.

Finally, consultation will merely be playing lip service to the notion of user participation without a constructive framework of resourcing users properly and making the process accountable.

The Living Options project in Derbyshire drew up the following checklist to assess an organisation's commitment to user involvement: (Gibbs and Priestley, 1995):

♦ Does your organisation want to increase user power?
♦ Are your staff required to demonstrate a commitment to user involvement?
♦ If you impose limits on user power, do you make these clear to everyone?
♦ Are your environments, processes and information accessible to disabled people?
♦ Do you involve disabled people's organisations as well as individual users?
♦ Do disabled people control your user involvement process?
♦ Do disabled people control your agenda for consultation issues?
♦ Do you provide user representatives with the same support systems as staff representatives?

♦ Do you communicate the outcomes of disabled people's involvement back to them?
♦ Has your organisation ever made changes against its will because disabled people wanted you to?

It would be interesting to hear the outcome of applying these questions to the members of Community Care Providers in Scotland.

Conclusion

I began by saying I was one of those stroppy 'ungrateful bastards'; and by now you may think I've proven my point. What I am saying, some may think, is okay for young, fit, well-educated and assertive physically impaired people - but not for those who are old; or have learning difficulties; or who are mentally ill, terminally ill, or just don't want to know.

But if we accept, as the independent living movement accepts, that all human life is of value, then it is difficult to deny that the human rights that we in the movement are claiming should also be accorded those others. And if we were to treat those, who are totally dependent on the care system for their security and safety, as social beings as well as natural ones, wouldn't their quality of life improve?

Community care policies must be measured against the objective of maximising the social being within us and promoting our duties of citizenship - rather than starting from the position that we all need 'taken care of', or 'taken charge of', i.e. in need of professional care. Even if a few do require greater supervision, to avoid damage to themselves, or others, is it not better to base services on the assumption that the person is a social being, with rights and duties?

To overthrow the welfare system and instate emancipatory services which promote and secure citizenship would require a wholesale redistribution of resources and power. To affect such utopia, would challenge the power, and even the existence, of whole professions, organisations and government departments. It would require universal access to the built environment; fully accessible public transport systems; an end to discrimination in employment; the abolition of 'special' education; and a complete restructuring of the social security system.

Such a revolution requires true equality and freedom of opportunity to express full citizenship by disabled people and networking with others both in power and in similar positions.

In a nutshell, what we really want is this. At the moment what is 'commonplace' to disabled people, e.g. ramps or communicating by sign language, is considered 'special' to those who exercise full citizenship today - able-bodied people. But if disabled people were to become full citizens then we would have a direct impact on the structures of society; we would influence the lifestyles of able-bodied people, like they shape ours just now. If that happened, then what is 'commonplace' to disabled people would no longer be seen as 'special' to able-bodied people. As Finkelstein and Stuart (1996) state:

> **"In such a dynamic interrelationship of equals, it would**
> **no longer make sense to identify disabled people's needs**
> **as special any more than, for example, to regard a**
> **stand-up urinal as a provision for the special needs of**

able-bodied men!' (Finkelstein and Stuart, 1996)

In conclusion, then, I hope I have kindled within you some spark of scepticism about whether all these latest initiatives in community care really do create within society disabled people's 'common place'.

Ask yourselves, as you eagerly sprint back to your afternoon seminars:

- If direct payments pass the test of meeting the criteria - the four pillars - of emancipatory services, then how does the care standards commission fare?
- How does the Care Development Group report measure up?
- What about the health plan, or the 'joint future' agenda, or social inclusion partnerships?" Are all of these just tinkering with the system, or do they actually lead to full and equal citizenship for disabled and older people?

Then, ask yourselves:

- How does my organisation, my profession, meet the criteria of emancipatory services?

And finally, if you dare, ask yourselves:

- To become full and equal citizens do disabled and older people need my organisation, my profession, alongside their own peer support, or do they just need personal assistants and joiners?

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