The Mac Keith Meeting, Royal Society of Medicine – 28th February 2005

The expert patient – Issues around the inclusion of an overlooked resource.

James Elder-Woodward

Biography:

Born with cerebral palsy, James Elder-Woodward has had life-long experience of disability, not only as a health and social service user, but also as a service provider, planner and researcher.

Educated at the Thomas Delarue School for Spastics before taking a degree in Psychology at Hull University, he has also studied health and social welfare in Sweden, Germany, Israel and Albania – as well as undertaking a short period of library research at the International Labour Organisation, in Geneva. In the UK he has worked for central government, local authorities, the health service, the voluntary sector and universities.

He retired from his post as Senior Social Work Officer in Glasgow City Council in 1999. Within that position he provided specialist advice to area social workers and local occupational therapy services, as well as managing residential care budgets, day care services, services to blind people, job coaches and independent living advisors. He was also liaison officer with service providers in the voluntary sector.

He set up indirect payment schemes throughout the West of Scotland, as well as establishing the Glasgow Centre for Inclusive living. Before retiring, he was seconded to re-provide services for disabled people affected by the NHS Young Disabled Units closure programme and care homes in the voluntary sector.

He is now the Vice Convenor of the Glasgow Centre for Inclusive Living, which supports 140 disabled people in Glasgow using direct/indirect payments; the Vice Convenor of Update, a Scotland-wide disability information and training consultancy agency; the Convenor of the Scottish Personal Assistant Employers Network (a peer support group of some 250

PA employers throughout Scotland); the Convenor of Direct Payments Scotland, a project funded by the Scottish Executive to encourage (a) Scottish local authorities to establish direct payment schemes; and (b) disabled people to take up direct payments and form themselves into local support groups; a Director of Inclusion Scotland, an intermediary body of 32 local organisations of disabled people in Scotland; the General Secretary for the British Council of Disabled People; a Board member of the National Centre for Independent Living; a member of Scope's Ezone; and Chair of Scope's IL zone

He lives with his disabled wife and dog close to Loch Lomond. Both he and his wife are supported on a 24/7 basis by a team of personal assistants.

Abstract:

Name, Degree, and Current Post

James Elder-Woodward, B.A (Hons): Retired

Title of Presentation

The expert patient – Issues around the inclusion of an overlooked resource

Aims

The paper sets out to discuss the inclusion of disabled people in medical matters as a bi-polar spectrum, with equality and co-partnership working, as crucial throughout. Also throughout the spectrum, attention needs to be paid to the language used and the tensions between the competing models of disability. At one end of the spectrum there is the doctor / patient relationship. Here attention needs to be given to the patient as an expert in the management of their own treatment and support. In the middle of the spectrum employment within health and social services is discussed. Here greater diversity in the workforce, particularly at senior management level is advocated; as is the need to reconfigure services and jobs to meet the real needs of disabled people. The rise of alternative systems of user-led independent living services is discussed and the reasons why these are not flourishing at present   And at the other end of the spectrum, practical ways

to involve disabled people in the development of policy and practice are analysed.

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Introduction

I was born in Scotland, at the same time as the NHS – so you could say we're twins.

Over the years, we have grown and developed in our separate ways. I shall pass on what I've turned into, but certainly the NHS is now large and self-possessing, confident in its abilities and assertive in its affairs

On its way, our relationship has been like that between any other twin siblings. We have helped one another, both practically and financially, with the NHS coming to my aid in times of crisis and me digging ever deeper into my pockets to bail it out. We have also squabbled with each other, our diverse interests clashing at times. At times it has been demure and caring towards me; at others it has been bombastic and overpowering; but at the end of the day, we have always been there for one another.

Nevertheless, particularly regarding the doctor / patient relationship, I still have an affinity with the more natural bond, which Dr Finlay seemed to have with his patients.

As you may know "Dr Finlay" was a character, of the pre-NHS 1920's, who appeared in a number of A J Cronin books, such as "The adventures of a little black bag", which later became the TV series, "Dr Finlay's Casebook". (Cronin, 1957)

Perhaps this romantic notion stems from the fact that A J Cronin was born in a village close to where I live and I can identify with the stories and characters he created.

The power Dr Finlay depicted was benign and always used to empower his patient and improve their physical and social situation. His interpersonal skills were also good, but it was his power, based on his relative wealth, knowledge, skills and perceived station in the community, as ‘the local doctor’, which opened doors and got things done for those among whom he lived. He was therefore seen as working for the community. If not quite as an equal, he was seen as being a fellow and a valued member.

He was a part of the community, not apart from the community.

This could not be said of Sir Lancelot Spratt, the NHS surgeon, created by Richard Gordon in his “Doctor” books, and later played by James Robertson Justice in the film adaptations (Gordon, 1955). Sir Lancelot’s bedside manner had much to be desired. He looked upon his patients as a bag of body parts; and their symptoms as just one part of a simple automatic cause and effect reaction.

Like Dr Finlay, the power Sir Lancelot exuded as he swanned down the ward with his dutiful train of nurses and junior doctors came from his money, knowledge, skills and position in society, but drew him apart from his immediate community.

So, why am I spouting forth literary criticism at a conference of doctors?

Well, I have come across both of these caricatures in my life as a patient and social work manager. I have met doctor’s who thought they were the “bees’ knees” and knew everything – yet created heartache, pain and discomfort in their wake. And I have met others who knew they don’t know everything but wanted to work with their patients to find the best solution for them. And I have met many others in between.

Both fictional doctors, to whom I have referred, had the same power, created by the same factors, so why is one seen to be inclusive and the other exclusive – why is one seen as being a part of and the other apart from his community?

You see the question isn’t just how do we include people – disabled or otherwise – within medical issues – the subject I was given to discuss – but how do we make medics and medical issues more inclusive, more receptive, to the lives of people.

Inclusion must be considered as a two-way process, with both directions having equal importance.

The difference between these two fictional characters is their relationship with those around them. Not only was Dr Finlay an organic part of his surroundings in which he saw and reacted to the whole person and dealt with their functional and social issues as one, but those with whom he interacted accepted him as part of their lives.

On the other hand, Sir Lancelot went to his factory workshop each day, sorted out a few dysfunctional body parts and errant students; then went home to his dinner parties and high society life. He was not accepted as being a significant part of the lives of his patients and students. He was ridiculed, as an 'outsider' by those around him.

Now, I'm not saying all doctors have to live in their patient's back room. But when relating to them, there needs to be some equilibrium in the relationship, some equal co-partnership to allow the bi-polar spectrum of inclusion to function properly.

Today, I should like to look at three parts of this spectrum of inclusion in some detail.

First: In this intimate realm of doctor / patient relationships. This is the end of the spectrum closest to the patients' lives

Second: In the field of employment. This is the middle of the spectrum – the public arena of social and economic commerce, where individual issues and professional issues meet within the cultural milieu of today's society.

And third: In the spheres of policy development and practice. And here we come into the professional domain of medics and medical issues – the end of the spectrum where most interest in the question of inclusion has so often lain.

But before I go on to consider each part of this spectrum in detail I should like to take a quick side step and look at two issues which are pertinent to the discussion of the whole spectrum; as well as any individual part of it – for it is these issues, which are particularly relevant to the social interaction between the doctor and the ***disabled*** patient; as well as ***disabled people's*** inclusion in matters medical.

These are language and models of disability. Their understanding and resolve are of prime importance to any intercourse between doctor and ***disabled person*** at any level and in any milieu.

Language

First, language: as John Humphries (2004) writes in his new book "Lost for words", language is power; and like power, it can be used well, or abused abominably. And, as Humphries also points out, those who abuse their power, usually abuse language in the process.

Language carries many messages; it categorises, labels and stereotypes. It can demean and devalue; it can dehumanise and debar.

But it can also include and empower; as well as exclude and disempower.

There are many examples of the misuse of language which debase disabled people. The obvious one is the denial of personhood, by using the adjective as if it were a noun**;** "the handicapped", "the paraplegic" are examples of this.

The "paraplegic" is also an example of words used to describe medical diagnosis, wrongly generalised to describe the entire individual. Other examples are "amputees", or closer to my heart, "spastics".

Such denial of the patients' personhood among doctors may be brushed aside as mere professional shorthand jargon, but the offence it causes only adds to the social distance between the two. This misuse of language can become a major factor to the exclusion of the disabled patient, not just within the one-to-one relationship of their own treatment and rehabilitation, but within intra-group dynamics, when working together during, for example, policy formation activities.

Another disempowering misuse of language is perpetrated by the transfer of a noun, which describes an artefact, associated with a disabled individual, to describe the individual himself. "How many **BEDS** does the home have?" or "**WHEELCHAIRS** go in that bus over there" are both prime examples.

Ignorance of the etymology of words is a major cause of this misuse of language and the resulting offence to disabled people. "Handicap" is a very negative term, here in Britain, but strangely not so elsewhere. Perhaps this is due to the word's etymology, which is somewhat disputed, but nevertheless has negative connotations within British social history.

Some say it derives from the 14th century tradition in horse racing, whereby a rider of a good horse had to race holding his "cap in one hand". Others say it comes from the 18th century custom of selling children to unscrupulous businessmen, who then mutilated their limbs, before sending them into the streets to beg with a 'cap in a hand'. However, in both explanations, the term 'handicap' means an acquired disadvantage, which it still does today.

The etymology of the word "cripple" is less ambiguous. It comes from the old Scots "cruppen", meaning 'to creep', or 'shrink'. "Cruppen doon" was used to describe old people burdened with age, so they creep along – all shrunken and bent.

As an aside and out of sheer bedevilment, I do sometimes wonder if there may be a need for doctors to call their 'patients', something else – or perhaps they already do! For the etymology of the word 'patient' goes back to the 14th century Old French word ***'patience',*** meaning 'suffering or enduring without complaint'. With the rise in the number of complaints against doctors, today, by those they call 'patients', I do wonder if 'patient' is still the right word.

However, to return to the issue at hand – denial of the disabled personhood in language reflects the values placed upon disabled people by society and those within, with power. Because disabled people have been seen as tragic figures of misfortune, unable to fit into the inflexible structures of society, most of them have been set aside from the rest of society, either by being incarcerated within institutions, or denied access to equal opportunities within the community at large.

Disabled people are seen as a debit on the balance sheet, instead of being socio-economic units within society which require resourcing. They are seen as something which needs to be paid for after profits have been made; a drain upon society which, as the recent 60th anniversary of the liberation of Auschwitz has highlighted, Nazi Germany had the ultimate solution

Yet, the disabled people's independent living movement has shown that even severely disabled people, adequately and appropriately resourced, can make a positive contribution to the social and economic fabric of society.

Disabled people do not need to be astro-physicists, bureaucrats, or computer analysts to prove this; although they have filled all these posts and more. They are also members of a family; tenants; tax-payers; artists; musicians; critics; thinkers; and that all important contributor to society – consumers.

Some commentaries (McKnight, 1977) have stated that even within the dependency creating services of today's health and welfare provision, disabled people have a socio-economic value as fodder for the maintenance of day and residential care and the creation of jobs for able-bodied people.

Models of disability

Definitions and the language they use are the basis of models. Likewise, the type of service developed depends on which model is being used. Within the field of disability two models generally compete for acceptance.

But again before moving on to discuss models two points should be made.

First, a model is merely a representation or illustration of a system or phenomenon, be it a building or a body. It does not define how that system works, nor how one part relates to another. It is a mere visualisation of the arrangement.

Second, there is a library of books and articles debating and refining these models. I am no academic, and there is no time to include a critical treatise of such arguments, so I propose to give a simple description of both and add my own penny's worth to the debate. However, I should give a health warning that both of these models are constantly being revised and as they are revised, their variegation is narrowing. For example the WHO is now introducing some of the aspects of the Social Model into a new Model they term ‘The Interactive Model’,

However, the first model, the Medical Model was developed by able-bodied people who generally exercise power and authority over the lives of disabled people, like your good selves. This World Health Organisation model in 1980 viewed our situation from their stand-point; the stand-point of those empowered by society to either "cure" or "care" – mostly in segregated institutions. It came from a perception of people who viewed "normality" in terms of able-bodiedness; from people initiated by a time and structure of health and welfare provision which denied choice, looked upon disabled people in terms of deviancy theory and had evolved from – but was still heavily influenced by – a poor law system based on partition and punishment. (WHO 1980)

The Medical Model defines our situation as follows;

"IMPAIRMENT" is “any loss or abnormality of psychological, or physiological, or anatomical structure or function”.

"DISABILITY" is “any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within a range considered normal for a human being”.

"HANDICAP" is “any disadvantage for a given individual (resulting from a disability) that limits or prevents the fulfilment of a role which is normal (depending on age, sex, and social and cultural factors) for that individual”.

Therefore, according to the Medical Model of disability, my impairment is my cerebral palsy; my disability is my speech, hands and legs do not function in a manner considered by others (others in authority) to be "normal for a human being"; and my handicap is I cannot perform the "normal" role of a bus passenger by running after a no. 49 as it drives off without waiting and hanging on as it goes screaming round the corner at 40 miles per hour.

Whereas the Medical Model portrays disability as being the relationship between the individual person and the impairment, the Social Model portrays disability as being the relationship between the individual and his environment.

The Social Model was developed by disabled people themselves in 1974. It comes directly from their own personal experiences; and therefore could be said to be more valid. It sees disability as something distinct from impairment. (UPIAS 1976)

"IMPAIRMENT" is “lacking part or all of a limb, or having a defective limb or mechanism of the body”.

"DISABILITY" is “the disadvantage, or restriction, caused by a contemporary social organisation, which takes no, or little, account of people who have impairments and therefore exclude them from participation in the mainstream of social activities”.

"DISABILITY", within the Social Model, is, therefore, a particular form of social discrimination.

So, according to the Social Model, my impairment is still my cerebral palsy, but my disability is society. It is the physical, psychological and organisational barriers within society which disable me.

Take away those steps and you take away my disability. Take away those negative attitudes and you take away my disability. Take away those inflexible, and often inappropriate, organisational systems and you take away my disability.

With my disability equality training colleague Kate Munro, I published a small book for care workers in 1992 (Munro and Elder-Woodward, 1992). We argued that one way of testing the validity and efficacy of models is to appraise their assumptions and outcomes. We compared and contrasted the assumptions and outcomes of one model with those of the other.

So, what are the assumptions and outcomes of both the Medical and Social Models?

First, what are the assumptions of the **MEDICAL MODEL**?

They are

- the person is in a tragic situation
- they have a loss and are disadvantaged
- their disability is part of the individual – it belongs to them
- it is their fault
- the expectation is the status quo of society is fixed, the person has to adapt to fit society;

Second, what are the outcomes of the **MEDICAL MODEL**?

They are

- a philosophy of 'cure or care' permeates service delivery; successful rehabilitation is seen in terms of the number of tasks that can be done without help, rather than the number of tasks which can be organised and directed with help
- the uncured person is segregated from the rest of society, and each other
- an industry of professionals and volunteers develops around the person;
- because of their physical impairments, it is generalised that their decision-making functions are also impaired
- the social control mechanisms of health and welfare services make sure that changes to the structure of society do not take place, because those who do not 'fit-in' are dealt with elsewhere

Now, what are the assumptions of the **SOCIAL MODEL**?

They are

- disability is not part of the individual; it is part of society's physical structures; it's psychological make-up and it's sociological organization
- disabled people are seen as an oppressed group
- society can change to be more accommodating to all minority groups

Finally, what are the outcomes of the **SOCIAL MODEL**?

They are

- disabled people can unite with one identity
- disabled people have the power to change society
- disabled people can integrate into society on their own terms than adapt to it on other people's terms

Therefore, in conclusion, it can be seen that the Medical Model disempowers disabled people; whereas the Social Model empowers them

However, Munro and Elder-Woodward (1992) concluded that unfortunately, we live in a society where

- the laws of the land are based on such a disempowering model – i.e. the Medical Model
- most of the traditional services, which are the outcome of such laws, are themselves, disempowering and,
- finally, where ***most*** professionals and others working within such services are trained to operate in a disempowering manner

So what does this say about inclusion?

As I said there is a whole army of academics debating these models; and the more they debate the less distinctive the models become. I feel sad about this, because in the struggle to find verity – truth – academics and professionals picking over these models have to some extent undermined the political struggle of disabled people to achieve equality and social inclusion.

The Social Model was – and still is – the greatest standard around which disabled people could – and still do – muster. Its continual erosion has sewn seeds of confusion and doubt in the minds of many, such that their motivation to continue the political struggle has become even more difficult to sustain.

However, Liz Crow’s analysis of the Social Model, in which she argues that it has ignored the importance of ‘impairment’ in the lives of disabled people, may help to rejuvenate such flagging motivation, as it re-kindles the debate on inclusion. (Crow, 1996) This is because – to some – their personal experience of impairment seems to have more impact on their lives, more relevance, than the political activities of DAN members demanding the eradication of disabling transport systems.

Time does not allow me to describe Liz Crow's analysis of the Social Model. Basically, she argues that by leaving 'impairment' to the domain of the medics, by concentrating on the socio-economic values of the removal of disability from society, followers of the Social Model have created two problems.

First, the current responses to impairment divide into four broad areas:

- avoidance / 'escape': through abortion, sterilisation, withholding treatment from disabled babies, infanticide, euthanasia (medically assisted suicide) or suicide itself
- management: in which any difficult effects of impairment are minimised and incorporated into our lives, without any significant change in our impairment
- cure: through invasive medical intervention
- prevention: including vaccination, health education, and improved social conditions

To this list I should like to add the current debate about the validity of 'quality of life indicators' which influence the medical practice of 'do not resuscitate'.

These responses have been driven primarily by the Medical Model and have fundamentally undermined disabled people's civil and human rights, including the right to live and the right to family life.

I feel Crow has been slightly overtaken in recent time, in that advocates of the Social Model are now turning to tackle the Medical Model approach to impairment. The present debate over the 'assisted suicide' bill in the House of Lords, spearheaded by Jane Campbell, is just one live example.

Hover, Crow's second point is the Social Model has overlooked the subjective experiences of impairment, such as pain, tiredness and emotion, which in themselves may inhibit participation and inclusion. Crow argues that integrating these key factors into the use of a broader and stronger Social Model may help to understand more fully the ways that disability and impairment operate. She concludes by saying:

> **“At this crossroads in disabled people’s history, it is time for this renewed approach to the social model and the way we apply it. Disability is still socially created, still unacceptable, and still there to be changed; but by bringing impairment into our total understanding, by fully recognising our subjective experiences, we will achieve the best route to that change, the only route to a future which includes us all.”** (Crow, 1996)

In a private email correspondence with Professor Colin Barnes of Leeds University, he said that the main criticism of her work is that the social model never ignored the significance of impairment and; that the emphasis on subjective experience is exactly that an individual experience and therefore is always open to misinterpretation and in so doing often re-enforces the idea of ‘personal tragedy’.

Pain and fatigue are not peculiar to disabled people, indeed, large sections of the disabled population do not experience physical plain as a consequence of their impairment - deaf people, blind people, people with the label learning difficulties are good examples.

However, most importantly, pain and fatigue are due to a variety of factors, both physical and psychological. They are frequently triggered by a variety of non physiological factors, such as economic and social.

Professor Barnes concluded in his email by pointing out that the multiple deprivations many disabled people encounter generates ‘psychological’ pain and exhaustion that cannot be addressed by medical or therapeutic interventions – they require socio/political solutions.

And so the academic debate continues.

But, it is not just an academic debate – it is a debate generated by disabled people, which disabled people wish to own once more. That is why, alongside their campaign “Time to get equal”, Scope is funding a project entitled “Time to think equal”. This is headed by Simon Stevens, who has cerebral palsy. He is the Chief Executive of Enable Enterprises – a training and consultancy firm – who won the Enterprising Young Brit Award of 2004.

The project is examining practical, social and cultural issues of impairments and conditions within a social model framework. The **aim** of the project is to bring together disabled people from all backgrounds to discuss the construction of impairment within a rights and social model context.

The outcome of the project will be a statement of values and beliefs, based on the evidence collected. The project hopefully will be a working model of impairment which could be used to provide a better understanding of impairment and disability as a lived experience; and which could be translated into practical applications, such as staff training and policy development.

Through discussion and debate with disabled people at many levels, the project will aim to achieve a consensus in creating such a working model or construct of impairment within a lived experience, and build common bonds across the disabled community in so doing.

But, to return to my original thesis on the bi-polar spectrum of inclusion – you will recall I wished to discuss three parts of this spectrum:

First: The intimate realm of doctor / patient relationships.

Second: The field of employment.

And third: The spheres of policy development and practice

Doctor / patient relationships

First: the doctor / patient relationships

As Alinsky said in his book 'Rules for radicals', published way back in 1971:

> **“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. …. To give people help, while denying them a significant part of the action, contributes nothing to the development of the individual. … It is not giving, but taking - taking their dignity. …”**

Doctors have been notorious for not including patients in the decision making process of their treatment and care. This may result from the possible desire to ‘protect’ the patient from bad news or from the uncertainty around diagnosis or prognosis. But such exclusion generally leads to a lack of trust within the patient and a social and emotional distancing between them and their doctors.

In a study by Begum (1996) on the relationship between GP’s and disabled women, she quotes one disabled woman recalling how her GP refused to even talk to her:

> **“Even though he knew I was going to university he still treated me like a child. Once when I was undressing prior to an examination I shouted answers over the screen to questions directed at my mother, which should have been directed at me. I was accused of being cheeky.”**

Begum (1996) also shows how such infantilisation is often coupled with an over generalisation on the part of the doctor of the disabled person’s inability.

From my own life history, I remember, at the age of 23 and after three years of learning to drive, without the luxury owning a car, I finally bought a car – a 1955 VW Beetle – to help me pass my driving test. However, I had to get a GP to sign a document stating I was capable of driving, before I could get insurance. Without checking on my driving skills, my GP wrote to Eagle Star, stating I could not drive.

This doctor’s decision came at a time when I had just left university and was entering the labour market. Getting car insurance proved to be an imperative. I had to be mobile to get and keep a job. I had already made 564 applications for jobs from as far afield as Aberdeen to Bristol; and my subsequent career confirmed my reliance on a car to carry out my duties. For example, as National Development Officer for Dial UK, my area of work covered Aberdeen to Truro. Without a car, I would not have been able to accept this or any of the other opportunities which eventually came my way.

This prejudiced judgement – which, today we would call ‘disablist’ – could have caused a major barrier to my inclusion within the labour market, let alone scuppering my social life. It had to be challenged. So my mother borrowed a wheelchair and pushed me eight miles to the local hospital and eight miles back. I had to go by wheelchair because we could not afford a taxi and I could not get on and off the two busses needed to get there – two more reasons why getting car insurance was so important.

We turned to my consultant orthopaedic surgeon who had cut my abductor chords, when I was six years old, because we thought he could refute the decision of the GP. Fortunately, his letter to Eagle Star had a more successful outcome than his operation.

However, Ignatieff (1984) in his book “The needs of Strangers” ponders the question, do we, as individuals, know what we truly need? Would it not be best to leave it to others – the so-called “experts” – 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 disabled people’s 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 occupational therapy 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 life.

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. Like Lear, all recipients of today's health and welfare services have to provide good reasons why their needs should be met and I definitely could do with more patience at times when such needs are not being met.

But why should Lear 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 the average patient would 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 depend 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 with 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)**

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 the consequences are. 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 of 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 traditional 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 their own care needs.

However, Marion Barnes (1999) Director of Social Research in the Department of Social Policy and Social Work, the University of Birmingham, argues that, whether or not the importance of experiential knowledge is theorized in the way that it has been within feminism or the disability movement, policy makers are now recognizing that effective interventions require a dialogue between the abstract knowledge of health professionals and the particular, situated knowledge of those who use services.

Rather than leaving the ‘choice’ of treatment to the individual patient, the notion of ‘shared decision-making’ as the means to achieving a higher quality of care and more effective outcomes, as well as rebuilding trust between clinicians and patients, is being advanced.

Barnes (1999) relates several studies which show this is effective in situations as diverse as health promotion initiatives with families living in poverty, treatment for women with early stage breast cancer and the provision of support for frail older people and their carers.

She goes on to say that the recognition of the legitimacy and usefulness of experiential knowledge has been helped considerably by the advocacy provided by those interest groups representing and supporting individuals in articulating and expressing their views and experiences.

Tudar Hart (1996) Research Fellow in the Department of General Practice, at Glasgow University, suggests that the way forward requires a return to the founding principles of the NHS, together with another missing from the original vision: the principle that professionals should be accountable to their patients as their intelligent partners.

Hart (1996) advocates that the aim should not be to rely on complaint and litigation after poor practice has been exposed (as for example, in the case of paediatric surgeons in Bristol), but for an expectation of direct accountability to patients, based in a reciprocal process of information and knowledge sharing, to be integral to the clinician/patient relationship.

Hart (1996) concludes that there is a continuing presence of user groups and other bodies outside the NHS providing challenges to professionalised and exclusive modes of decision-making. But there is also a growing commitment amongst some NHS workers that the interests of the service and the interests of the user will best be met by working together, rather than in opposition. If both work together, they will continue to provide an impetus for change.

In 2001, in a paper entitled “***The Expert Patient”,*** the government finally set out what it termed ‘a new approach to chronic disease management for the 21st century’. This notion was first put forward in the white paper ***Saving Lives: our Healthier Nation*** and then reaffirmed in the NHS Plan. (DoH, 2001)

The paper has two premises:

First: the predominant disease pattern in this country is of chronic rather than acute diseases.

Second: today's patients with chronic impairments need not be mere recipients of care. They can become key decision-makers in the treatment process.

The report states that the era of the patient as the passive recipient of care is changing and being replaced by a new emphasis on the relationship between the NHS and the people whom it serves – one in which health professionals and patients are genuine partners seeking together the best solutions to each patient's problem, one in which patients are empowered with information and contribute ideas to help in their treatment and care.

Against this background the paper states that the challenge for the NHS is to bring about a fundamental shift in the way in which chronic diseases are managed - a shift which will empower and liberate patients to play a central role in decisions about their illness.

The key means of making the shift is called 'self-management programmes'. Here, patients have been empowered through information and training to take control of their own treatment regimes. Patients are also encouraged to do what they feel comfortable with and with what they think works for them. Some of these programmes have already been developed in the USA by Professor Kate Lurig at Stanford University and also in this country by organisations such as Arthritis Care.

The changes promoted by these new programmes are expected to bring about health benefits, such as the reduction of pain and morbidity. Other gains have been found in the increase in the rate of return to employment by patients; and a reduction in the use of continued health care.

Employment:

Now, in my discussion on the spectrum of inclusion, I turn to the field of employment

After two years of post graduate research at Lancaster University, I applied for a job as Trainee Social Worker with the Scottish Council for Spastics. I was hoping to get a ‘professional’, in inverted commas, qualification to allow me to teach and research at a university. After being interviewed by all twenty four members of the West of Scotland Committee, I was offered the job.

I thankfully turned down a research officer’s job in Great Yarmouth to head north. Only, the day before I left to head north, I received a letter from the Scottish Council, stating they had reconsidered their offer and wished to withdraw it. On enquiring why, I was informed that the Principal Social Worker, who wasn’t present at the interview, considered that I was too close to the problem to be a ‘professional’ social worker. There then lasted a six month period of anxious unemployment, until I managed to find a temporary research post in Banff County Council.

‘Being too close to the problem’ has been a major attitudinal barrier in my career development within social work. The predominant opinion that there should be some ‘objective distance’ between ‘professional’ and ‘client’ has resulted in chronic institutional discrimination within health and social welfare services over the years. I also contend that this is also a major reason why resources from local authority social services have not been transferred to user controlled independent living support organisations. There seems to be a mental block among quite a number of professionals in these statutory bodies to the idea that disabled people can and want to run their own affairs.

Thankfully, this is now beginning to be addressed in some quarters. The European Social Network is an organisation of national associations or groups of directors of local authority social services, social protection and social welfare from around 20 European countries. The Network is politically independent of national, regional or local government. In some countries directors also manage health or other services such as education and/or housing.

At their annual conference in Gothenburg, in 2003, Dr Jane Pillinger, an independent researcher and policy advisor from Dublin, presented a paper entitled; ‘Managing diversity in public health and social care in the interest of all citizens’.

Pillinger (2003) states that the low level of disabled people in the health and social service workforce is a consequence of a range of factors, including prejudice, lack of education and training, inaccessible workplaces, lack of support and low pay.

Her report highlighted the fact that health and social service organisations have been slow to address the needs of disabled staff and to encourage the higher participation of disabled people in their employment.

There appeared to be few examples of initiatives to support and develop disabled staff, particularly into managerial and senior positions. Nevertheless, the diversity in the workforce in the public sector has become an increasingly important objective that is linked to two important goals – notably, the improvement of equity within organisations and improvements in service delivery.

Many European governments, health and social service agencies are now implementing or considering plans for diversity in organisations by enforcing greater workforce diversity for disabled people and in some cases, at managerial and senior levels. The objective is to match the public sector workforce to the customer base and the profile of the community at all levels. In some countries specific performance objectives and diversity management plans have been developed.

There are a significant number of employment policies for disabled people many of which have been influenced by the EU's Employment Guidelines as well as national developments. These include special schemes to provide work experience, start-up grants for self-run businesses and self-employment; grants for the adaptation of the work place; grants for work adaptation and technical aids, and grants or personalised support, including tutors, job coaches or personal assistants.

In practice very few health and social services organisations have disabled people in senior and managerial positions. The percentage of the general workforce that is disabled is also relatively small. The ESN survey found that this ranged between 1% and 3% of the total workforce.

The ILO Code of Practice on Managing Disability in the Workplace (2001) is an example of the importance now attached to managing disability. Health and social services now need to place a greater emphasis on managing disability at work as a means to improve the quality of the workforce and their ability to deliver to customers in effective ways.

Pillinger (2003) states there is a need to develop a more strategic approach and build best practice, foster leadership and cultural change, improve community engagement and support progress.

Equal opportunities monitoring has become important to the overall achievement of equality in the workplace. But achieving equality means going beyond the collection and analysis of data to assessing the effectiveness of an organisation’s policies, processes and practices. Monitoring can only help to provide a picture of the composition of the workforce, where particular groups are under-represented and help organisations to make the best use of their staff.

Pillinger’s survey (2003) for the European Social Network found some evidence of policies to support the employment and career development of disabled people in health and social service organisations. However, these policies rarely seemed to translate into practice given the continuing low level of employment of disabled people in senior and managerial positions.

She advocates that a key role for the future of health and social care services should be to ensure that there is integration and coordination within the full range of services that are essential for participation in society.

Providing for more diverse workplaces and more accessible and user focussed services means exploring how barriers to participation in society at large can be overcome; and how quality improvements can lead to real improvements in both the employment of disabled people and access to services. The two must progress together.

Another important issue, which Pillinger (2003) identified, was the development of more effective evaluation and information systems so that service needs can be identified and translated into service planning and workforce planning. This is essential to the provision of quality services which map services as they develop and measures issues such as equity of service provision, local needs assessment, service and workforce planning.

Pillinger (2003) further argues that organisations must ensure they are more accommodating of equality and diversity, including the development, assessment and implementation of policies relating to disabled staff within a broad diversity framework. There is also a need for better knowledge and awareness about the benefits of valuing and accommodating diversity in the area of disability so that disability issues can be mainstreamed throughout all areas of the organisation and championed at senior levels.

Similarly, there is a need to establish fora for disabled employees for the exchange of ideas, good practices and for support. There is a need for policies and mechanisms to support and develop staff. Finally, raising the awareness of everyone in the organisation will be important to promoting a culture that accommodates and promotes diversity.

Such policies are already being implemented by Scope, one of the largest social welfare providers in England and Wales

Scope has set itself a target of employing 20% of disabled people by 2008 – the current figure is about 4%.

20% is the percentage of disabled people in the potential workforce at large, and as a disability organisation, Scope wishes to reflect the society in which it operates.

To achieve this target Scope has undertaken the following action:

- It has instigated a reserved posts policy – designating posts which are only open to disabled people; and where being a disabled person is essentially a job requirement
- It has adopted the two ticks symbol which encourages applications from disabled people
- It provides mandatory DET for all staff
- It has created a database of disabled people interested in working at Scope, which means its full vacancy bulletin is sent on a regular basis to all those on its data base, thus targeting potential disabled candidates
- It has made the target of 20% one of the departmental business plan targets, on which departmental managers will be monitored
- It has produced a managers' guide on employing disabled people

- And finally, it is coordinating all work on reasonable adjustments and Access to Work bids.

But, I contend this is not enough. As Pillinger (2003) states, service planning and workforce planning should reflect service needs. Therefore, ‘fitting in’ disabled people to existing structures and existing jobs, may not meet the real needs of service users. There may be a need for different structures and different jobs.

In a paper given at Leeds University Centre for Disability Studies in 2001, Vic Finkelstein reflected that the people who have a real influence on political decision-makers are the people who work in the disability ‘industry’; care managers, social workers, occupational therapists and doctors.

Finkelstein (2001) says – and I quote:

> **“…. they present a catalogue of assumptions about disabled people’s inadequacies which are compatible with the status quo agenda for social organization set by present day parliamentarians. As long as disabled people’s influence is not structurally rooted in the health and welfare sectors of society they cannot expect to have the same real impact on society in their own terms – i.e. they will remain ‘socially dead’.”**

He was of course referring to Millar and Gwynne’s (1972) description of disabled people’s status within residential care, which Finkelstein generalized to all disabled people receiving care services.

He goes on to state:

> **“My view, then, is that the only way we can gain real influence is by finding a means of entering the health and welfare labour market *in our own terms* – i.e. by developing our *own* profession. ….. many of the elements for us to go to the next stage and begin developing our own profession from our own perspective have already matured. All that remains is for us to fire the imagination of the disability movement in supporting the venture, expanding our personal confidence in the emergence of disability culture within which to locate such a profession, and the academic will for curriculum development critical of**

> **‘compensatory’ approaches to disability-related service development.**
>
> **(Traditional) compensatory ‘care’, benefits and equipment are provided to enable our access into the able-bodied social and physical environment. This is contrasted with an approach to intervention which introduces our perspectives and culture into the structures of society so that provision is made more accountable to a multi-cultural population. The contemporary (**Professions Allied to Medicine **(PAMs)) work within the compensatory care framework. What we really need, however, is to create a *Profession Allied to the Community* (PAC) – i.e. designated community workers who are allied to particular groups that are disadvantaged by the way that the social and physical environment is constructed around the dominant values. I think the creation of such a profession is the *central challenge* that disabled people face today. In my view there are now a number of factors in our favour for beginning this undertaking. One such factor is the collapsing health service. The unraveling of the National Health Service (in reality a National Medical Service) has provided us with a window of opportunity to intervene in restructuring service provision. Exactly how we are to do this is the challenge that should occupy our critical faculties.” (Finkelstein, 2001)**

The development of Centres for Independent Living, or Centres for Inclusive Living, has been slow in this country, but these are the types of services with the types of personnel having the types of job description, Finkelstein envisaged. In America, Europe and Scandinavia, the growth of this type of provision has been more rapid. One reason for this must be the institutional power of health and welfare services and the professionals they employ, which has been bestowed upon them by the British state.

Theirs is the money, the power and the glory – but, hopefully, not for ever and ever.

Barnes, Mercer and Morgan (2002) carried out some research on such ‘user-led’ organizations, such as CILs. Their findings included:

- Government initiatives indicate a clear intention to increase the use of direct/indirect payments by disabled people, carers and other health and social service users.
- Government now expects disabled service users to be fully involved in developing the new landscape of Health and Social Care.
- If this is to be a realistic goal, then it needs to be resourced and requires a systematic structure for sustainability.
- Due to a serious lack of public and private investment; user created structures of CILs, networks and coalitions have been systematically compromised and their framework is fragile, regionally variable and seriously over stretched.
- Investment through funding and capacity building for existing user controlled services is a cost effective, rational way to “place service users at the heart of social ‘care’” – a stated Government policy.
- Although mainland Britain’s network of user controlled services is more than twenty years old, its future development is seriously inhibited by a range of economic, political and social factors.

Among their other additional findings there is an indication that:

- User-controlled services organized around independent living take a variety of forms and date back to the early 1980s.
- There is a symbiotic but often uneasy relationship between user-controlled organizations and sponsoring agencies such as local authority social service departments and health authorities that often inhibits the further development of user controlled support.
- Funding is a major problem for all user-controlled support services. It is generally short term in nature and in the overwhelming majority of cases limited to the development of particular projects.
- This has important negative implications for the type of premises used, the numbers of staff employed and the type and long term availability of the services offered.
- Competition for service contracts from national and local nonuser controlled agencies has intensified over recent years and further threatens the future development of local user controlled support.
- There is an urgent need for the development of core funding strategies by Central Government to enable the further long term development of local user controlled support services.

- User controlled organizations have an exemplary record for employing and training disabled people for work as independent living support workers and related skills.
- There is a pressing need for further benefit reform to enable disabled people to take full advantage of the growing employment opportunities within user controlled support services.
- There is general disquiet amongst both users and providers of user controlled services about the lack of information on the availability and benefits of independent living and related services in the public domain.
- Less than half the user participants in the research had been referred to user controlled services by representatives of statutory agencies such as local authority social service departments or health authorities
- There is an urgent need for a national marketing campaign to raise public awareness of the benefits and advantages of direct payments and user controlled support services for independent living.
- There is general concern amongst all those involved in the development and delivery of user controlled support services over Government proposals to bring together medical and social provision as 'care trusts'. This is because, hitherto, health authorities and medical professionals have shown little understanding of the benefits of independent living type services for disabled people or their families.
- There is an urgent need for clear and unequivocal guide-lines on the establishment of care trusts to ensure that professional interests and concerns are not prioritized over those of users and/or user controlled organizations. Care Trusts must not mean no trust in disabled people.
- Disabled people must have the right and the responsibility to control their own ‘care’ packages and the support services that enable them to do that.

To conclude this part of the discussion, I must say that I look forward to the day when health and social services are taken out of the ambit of local politics and accountability for them is placed squarely within those who use them. Even health services are subject to a postcode lottery, dependent on the whims of locally appointed people, with little accountability to and seemingly less interest in those whom they serve.

Perhaps the next parliament – after the election – will move in this direction. I am certainly not a New Labour supporter, but I do hope that whichever party gets into power in May, they will implement the No 10 Strategy Unit's report, "Improving the life chances of disabled people" which has just been published. Its emphasis on independent living and the involvement of disabled people in the management of their own affairs has much to recommend it. (Prime Minister's Strategy Unit, 2005)

Policy development and practice:

This brings me to my final section of the bi-polar spectrum of inclusion: the spheres of policy development and practice.

Policy in health care is usually formed by government appointed committees. If you look at some major committees – such as the Tunbridge (1972) and Mair (1972) Reports on Rehabilitation or the Williamson (1982) Report on Wheelchair Services – you will find the committees crammed with doctors and nurses, bureaucrats and academics; but not one disabled person. Yet these services – rehabilitation and wheelchairs – are crucial to the lives of disabled people, most of whom are just as 'expert' on the subject as those appointed by the government.

Again, if you look at the membership of health boards and trusts – those bodies concerned with local policy and practice issues – you will not find many representatives of the lay population on them and even less of the disabled lay population. Yes, there is government commitment to have 4% of health board and trust membership filled by disabled people. But, and it is a big but, the government has stated quite openly that although it monitors the appointments of women and black people, it does not monitor the number of disabled people.

In addition, there is still no capacity building programme undertaken by the NHS to develop interest, skills and commitment among lay people generally, let alone disabled people in particular, in the affairs of health organisations. Nor is there any effort on the part of health organisations themselves, to make participation within their governance open and accessible. Without such intrinsic and extrinsic support, user involvement in the development of health policy and practice will be stunted.

The recent exercise in creating care standards in Scotland 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 Scottish Social Work Services Inspectorate commissioned Dougie Herd and Kirsten Stalker (1996) to write a report describing good practice in involving disabled people in service planning, purchasing and providing. Unfortunately, the Executive took little heed of their recommendations in this particular development of care standards exercise. In fact, I 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 – such as doctors, nurses, care managers – 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.

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. But more importantly the involvement of users in policy and service development should not be a one way process.

Powerful policy-makers and providers tend to treat the consultation process as a presentation of ideas and solutions to users as **a *fait accompl*i**, merely for comment and discussion. The consultation process should be two-way. Those who wish real involvement of users need to listen to their agenda – at times and places suitable to them; and in a manner, or methodology, convenient to them.

Nevertheless, it is important to involve users in:

- Setting service standards
- Writing service specifications
- Assessing service performance
- Reviewing service performance
- Agreeing action for continuous improvement
- Service planning / performance planning

Fundamental to the entire process of user involvement is good quality information not just about services, but processes as well.

Before providing such information, however, certain key issues require to be considered:

- **WHY** is information being provided
- **WHO** is it trying to reach
- **WHAT** is it hoped to achieve
- **WHEN** is it appropriate to disseminate the information
- **WHAT** are the needs and capabilities of the target audience
- **IS** the language and presentation clear
- **CAN** the process be undertaken in co-operation with other services
- **CAN** there be co-ordination with existing provision or initiatives
- **IS** the information in multi-media format

Information is a crucial ingredient in all forms of user participation, not just consultation.

As d'Aboville (1994) points out, it is imperative that these different forms of participation should be followed according to:

- **WHO** is being consulted
- **WHAT** is the purpose

- **WHAT** is the expected outcome
- **WHAT** is the timeframe

Etienne d'Aboville, (1994) wrote a report on a seminar, called 'Promoting User Involvement: Ideas into Action', which details a sequence of user involvement, which, incidentally supports the thesis of this paper that inclusion should be considered as a bi-polar spectrum of interaction.

This sequence starts with basic

- **Provision of information** – how and where decisions are taken and by whom? What services are available and how else could needs be met?

It goes on to describe

- **Individual consultation** – individual users expressing their own needs and how they think these could be met.
- **Group consultation** – groups of existing or potential service users can be consulted about what kinds of services are needed.
- **Joint working** – service users working in partnership with professionals on, for instance, writing service specifications, or setting quality assurance measures.

And finishes with

- **Delegated control** – where statutory agencies delegate control over key decisions or services to individuals or user-led organisations

Instances of where each type of user involvement was operating are provided, alongside the discussion. There is too much information to repeat in this paper.

In April 1993, the Department of Health's Community Care Support Force published a pack recommending ways in which health and social services could promote user involvement in community care services. The National User Involvement Project was set up following this publication to help authorities implement the recommendations. (Morris and Lindow, 1993)

The Project was run by people who had experience both in using services and of carrying out consultancy work with health and social service agencies. Over a period of eighteen months four local projects were set up to involve users in the decisions about what services were bought on their behalf.

The Newham Project identified the following service outcomes of user involvement.

- Better targeting of services and greater effectiveness
- Maintenance of good quality services and better monitoring possible
- More efficient use of resources over the longer term
- Better planning of services to meet people's needs
- More accessible, empowering and culturally appropriate services.

User Involvement not only improves the quality and appropriateness of the service but also increases the personal development of the individuals concerned, for they feel empowered and valued by the experience. This can be seen in a quote from a disabled service user who was part of a user involvement project in Dudley:

> **"They inspired me to this uniting all disabled people and making someone sit up and listen …… it sounds dramatic, but they seemed to kindle some flame for me. I suddenly as it were, saw the need and want to do something about it. I wanted to be a pioneer, I wanted to be Martin Luther King, you know … what's the phrase, I have a dream … don't we all."** (Lindow, 1996)

Jenny Morris (1996) a disabled researcher and author, gives the following reasons why user involvement should be encouraged in commissioning:

- It is an essential tool in creating good quality and cost effective
- It enables commissioners to be accountable
- It is a key resource in the development of the commissioning role
- It is necessary in order to carry out statutory responsibilities.

She also gives examples of where and when user involvement is appropriate, including:

- Finding out what is needed (new ideas)
- Writing contract specifications
- Inspection of services
- Appointment of staff
- Management committees
- Commissioners' forums
- Writing and monitoring complaints procedures
- Assessment procedures and processes

Commissioners within health and social services, Morris (1996) argues, could increase user involvement by contracting services with user-led providers; as well as delegating control of budgets to individual users (through mechanisms such as direct payments, care management, or service brokerage).

Finally, she also discusses the foundations and infrastructure necessary for user involvement. Here she gets to the kernel of the debate between consultation and negotiation in decision-making. She asserts that there are three cornerstones to user involvement:

- Information
- Communication
- Decision-making

Morris (1996) writes:

> **"The exchange of information between users and commissioners, the opening up of communication between the two groups, and the involvement of users in decisions – all these promote the ability of commissioners and users alike to make informed choices about how best to meet need."**

Therefore, the general aim of any exercise in user involvement should be:

- To increase information between users and commissioners about each other

- To promote communication
- To enable users to be part of the decision-making of commissioners (and thereby accept accountability)

This will lead to the general goal of opening up choices available to both users and commissioners. It is important not to lose sight of this, otherwise exercises in user involvement will become an end in itself – rather than, as it should be, a means to an end.

Morris (1996) also raises some issues regarding the infrastructure of user involvement, in the form of questions, which commissioners need to address within their organisations:

- Are the assumptions and anxieties of commissioners getting in the way (e.g. the worry about raising expectations)?
- Do commissioners have the relevant skills, understanding and experience (e.g. knowledge of the 'social model', and models of user participation, awareness of disability politics)?
- Is there a budget (e.g. for travel, assistance, alternative media and, importantly, payment to the users for their time and effort)?
- Do service users and their organisations have the relevant knowledge, skills, and resources (e.g. relating personal experience to general policy)?
- Are those who facilitate user involvement at meetings, etc, clear about what they want to achieve?

With all of these issues the main expedites are money, training, and experience. Organisations will be merely playing lip service to the notion of user participation without a constructive framework of resourcing users properly and making the process accountable.

However, no matter how much money and other resources are thrown at user involvement, it will be a meaningless and wasteful exercise, unless there is commitment to treat disabled people as equals. Equals: with a valid and knowledgeable viewpoint. Equals: with the same commitment to best value and high standards of service.

This notion of 'an exchange of equals' has been championed by the think tank "Demos". Scope commissioned a study by Demos into how 'disablism' could be tackled within society at large. Demos looked at the field of science, where an attempt to bring together scientists of different disciplines and different outlooks to solve common problems was bing developed by Harvard Professor Peter Galison.

He set up 'trading zones'. These were not places for commercial exchange; but exchange of equalities. As the report states:

> **"The 'trading' metaphor shouldn't be thought of in shopping mall terms. It supposes equal exchange, rather than a consumer-based understanding of commerce where people are excluded by virtue of their income or status. It is a place where people come together bringing with them something of value, be that resources, skills, experience or ideas, and after exchange and interaction leave with something of benefit."** (Miller, Parker and Gilinson, 2004)

Scope has now taken this concept of 'trading zones' and set up two fora with individual disabled people, of which I am the member of one and chair of the other. These 'zones' cover each of disabled people's equality within society at large; and the development of independent living opportunities for Scope's residential care users, supported by user-led community-based groups.

However, to return to the practicalities of user involvement, as an aid, the Living Options project in Derbyshire (Gibbs and Priestley, 1995) drew up the following checklist to help managers assess their organisation's commitment to user involvement:

- 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 this 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?

Finally, d'Aboville (1994) asks health and community care organisations to distinguish between when it would be appropriate to encourage the participation of an individual user and when they need to ask someone who represents users. Individuals may be able to represent themselves, for example, in the process of their own assessment and care management, i.e. when matters being discussed are pertinent only to that individual.

However, individuals can only authentically represent other service users in, for example, the commissioning process, if they are accountable to a group or organisation of service users. It would be even better if that group or organisation had supplied their representative with data from a survey or piece of outreach work, which they had done beforehand.

Perhaps it would be best to look at four basic issues underpinning user involvement. (Begum and Fletcher 1995)

- **Defining user involvement**
- **Resourcing user involvement**
- **Integrating user involvement**
- **Evaluating user involvement**

Under **'defining user involvement'**, to avoid the term being used as a meaningless buzzword:

- Be clear about what user involvement means in terms of each person's work in the organisation
- Produce information for workers on the different types of user involvement with examples of when it may be appropriate to use them

- Select an area of work, which needs to be looked at – such as equality training – and work alongside an organisation of disabled people to tackle it
- Work alongside user-led service organisations to learn from their approach

Under **'resourcing user involvement'**, as well as reiterating once more that those users involved in planning should not only receive practical resources (e.g. transport, facilitation, meeting venues) but remuneration for their services, Begum and Fletcher (1995) state that those seeking user involvement should look at:

- Setting up contracts with organisations of disabled people to carry out some joint working task, such as a review of services – and pay them to cover their core and development costs.
- Developing campaigning forums of disabled people
- Offer disabled people specific training, e.g. in service specification
- Provide training to staff in user involvement

Integrating user involvement into the mainstream of service delivery is very important. It has been asserted that groups of disabled people should be able to run their own services or be involved in the inspection and evaluation of services run for them

Finally, user involvement will not see immediate effects and those who participate in it may get somewhat demoralised. Therefore imperative that within any user involvement project there is an ongoing process of **evaluation and feedback.**

Methods of user involvement may include:

- Open meetings (open to the general public)
- Meeting(s) with a targeted group of users for a specific purpose
- Researching / surveying the views and experiences of user and potential users
  Outreach work / development work (interviews, think tanks, etc)
- Setting up user groups (quality circles, etc)
- User representation on committees / planning groups, etc
- Users as inspectors / evaluators of services

- Commissioning user-led services
- Delegating control of budgets to individual users (direct payments, service brokerage schemes, etc)

It would be remiss of me not to discuss the issue of multiple discrimination. The involvement of disabled women black disabled people and gay disabled people has not been highlighted much in this discussion.

The issue of women in the labour market having their own identity and making their own contributions, which generally enhance the employment scene that they are in, has been noted elsewhere. However, the multiple discrimination of disabled women in the labour market has yet to be fully tackled.

Similarly, race and disability is not simply an issue of 'political correctness', but a statutory responsibility to which health and social care agencies need to respond.

I don’t have time to expand this issue, but here is just a summary of the strategies and action plan of one group of disabled people in Warwickshire, to include black disabled people among the midst. (Evans and Banton, 2001):

- Provide good physical access, a comfortable, welcoming venue and appropriate transport
- The goal should be to make all mainstream services accessible, inclusive and encompassing of diversity, but provide a choice between separate and mainstream services.
- Develop an effective action plan to include joint agency work, realistic target setting, race and disability training for staff and regular consultation and evaluation with black disabled people.

But before practical work can begin, organisations need to have:

- Committed people to take the work forward
- Pro-active attitudes and an awareness of the issues
- A recognition of the impact of multiple oppression
- An organisational structure, which supports different types of involvement and movement between them

Conclusion:

In conclusion, therefore this paper has set out to discuss the inclusion of disabled people in medical matters as a bi-polar spectrum, with each end of the spectrum having equal weighting and with equality and co-partnership working, as crucial throughout.

Also throughout the spectrum, attention needs to be paid to the language used and the tensions between the competing models of disability

At one end of the spectrum there is the doctor / patient relationship. Here attention needs to be given to the patient as an expert in the management of their own treatment and support.

In the middle of the spectrum employment within health and social services was discussed. Here greater diversity in the workforce, particularly at senior management level was advocated; as was the need to reconfigure jobs to meet the real needs of disabled people. The rise of alternative systems of user-led independent living services was discussed and the reasons why these were not flourishing at present

And at the other end of the spectrum, ways to involve disabled people in the development of policy and practice were analysed.

This paper has postulated some ideas to develop user involvement projects. Any strategy to involve disabled users must be developed alongside disabled people; and should follow the recommendations set out by both the National User Involvement Project and the Living Options Project.

By involving disabled people in planning and providing services, services will become more appropriate to their real needs and therefore will meet the criteria of best value more closely.

It is also predicted that the disabled people who participate in user involvement programmes will identify with the service more closely and feel some accountability and responsibility for them.

In addition, it is hoped more will also experience some personal development and life enrichment. As one of the steering group members on the National Users Involvement Project writes, getting involved is

> **"…. exciting and stimulating. People have told us that it has changed their lives. For the first time, they say, they feel they are in charge of what happens to them, know what they really want and are doing something important. They have learnt new skills and done things they had never done before, or even thought they would be able to do. They have made new friends, found new sources of support and feel they are really making a difference."** (Croft and Beresford (1993)

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