

# The Scottish Community Development Centre

## One Day Conference - Social Work: Inclusive or Exclusive

**Workshop Paper: Social Work and Disabled People: From crafting clients to sustaining citizens.**

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### Abstract

During the last quarter of the last century, social work theory and practice in the field of disability has been greatly influenced by the values and philosophy of the Independent Living Movement. This movement has shifted practice from the creation of clients dependent on services controlled by professionals, to working in partnership with disabled people to secure their rights as equal citizens of the state. This workshop will look at the process of this change by discussing methods to include disabled people at the macro level of planning, purchasing, providing and monitoring of services, as well as the micro level of assessment and care management.

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### Client v. Citizen

In the past, disabled people's general perception of medical and social care professionals has been one of the powerful, domineering gatekeeper of resources - sometimes vital resources - which could improve the quality of life and facilitate equality of human rights and citizenship (Lindow and Morris, 1995).

Such a perception has been engendered by the power bestowed upon such professionals by the Welfare State. Welfare legislation and ensuing procedural guidelines steered away from the idea of supporting an active citizenship within a framework of entitlements, which had originally underpinned the philosophy of the Beveridge Report (1942). Instead, the Welfare State, as maintained by some commentators like Michael Ignatieff (1989), has led to the creation of passive recipients of care and benefits, which are meted out by a heavyweight bureaucracy, according to some nebulous notion of 'need'.

But it has been professionals within such bureaucracies who have been seen as deciding - what is '**need**'; who is in '**need**'; how much '**need**' should be met; and the manner in which that '**need**' should be met.

They have also been accused of concocting terminology to reinforce their dominance over those their industry has been designed to support. When discussing the process of professionals 'crafting' clients out of disabled people, Davis (1993), a disabled activist, states: "**Thus, it has come to be that the disability 'professionals' and us, their 'clients', live within the carefully crafted, mechanical embrace of 'care'.**"

Davis (1993) advocates that part of the process of gaining control over our lives involves us - disabled people - resisting the efforts of professionals to box us into the pigeonhole of 'client' and, as he states: "**to elevate their second-hand knowledge about disability into a profession**".

It has been argued that the term 'client' gives the disabled person dignity and status. Indeed, lawyers and architects use it with relative neutrality. So, why not social care professionals?

Part of the answer lies in the etymology of the word. 'Client' comes from the Latin 'Cliens' - 'to hear' or 'hearken'. Therefore 'Client' was used as in 'one who is at the call of ...' In the Roman Empire, a 'client' was a plebeian (a commoner) under the patronage of patrician (such as a Senator). The patron was bound to protect his client's life and interests, in return for immediate menial services from that client.

This power relationship, as existed between patron and dependent retainer, is much more evident in the relationship between the recipient and providers of care services, than that between the recipient and provider of legal or architectural services. Perhaps this is because, not only are there choice and a direct financial transfer within the latter relationship, both of which aid the balance; but in the former there may be some legal, emotional, or physical compunction on the part of the recipient to enter the relationship.

With the introduction of the NHS and Community Care legislation the concept of 'empowering' users of social care came into vogue. The Department of Health Social Services Inspectorate and Scottish Office Social Work Services Group (1991), within their joint publication, "Care Management and Assessment: A Practitioners' Guide", lists the values underpinning community care. These are:

- ◆ A commitment to ensure that all users and carers enjoy the same **rights of citizenship** as everyone else in the community, offering an equal access to service provision, irrespective of gender, race or disability
- ◆ A respect for the **independence** of individuals and their right to self-determination and to take risks, minimising any restraint upon that freedom of action
- ◆ A regard for the **privacy** of the individual, intruding no more than necessary to achieve the agreed purpose and guaranteeing confidentiality
- ◆ An understanding of the **dignity and individuality** of every user and carer
- ◆ A quest, within the available resources, to maximise **individual choice** in the type of services on offer and the way in which those services are delivered
- ◆ A responsibility to provide services in a way that promotes the realisation of an **individual's aspiration and abilities** in all aspects of daily life

### **The independent Living Movement**

But where did all these buzzwords come from - 'rights', 'choice', 'privacy', 'dignity'. Where the politicians and social care professionals suddenly struck by lightning on the road to Damascus?

No, not really. Most change in social policy has been structured from the clamour of people outside the cohort of such professionals and politicians. It is clear that the

impetus for the 1990 NHS and Community Care legislation came from the right-wing of the Conservative Party, in their desire to reduce public spending. However, much of the clamour for moving power from an autonomous 'state' of welfare, to an autonomous 'state' of the older or disabled individual came from the Independent Living Movement.

The movement has been described as the last international civil rights movement. In fact, the slogan of one group of disabled people in South Africa is '**To boldly go where everyone else has been before**'.

The movement meets all four elements of what is called 'a new social movement'. It is **not affiliated to any one political party**, which is the first element. It is consciously engaged in **the critical evaluation of society and the redefining of problems**, which constitute the second and third; and it also **creates alternative forms of participative social provision**, which is the fourth (Oliver, 1990).

Not only has the movement **redefined 'disability'**, but its critical evaluation of the social care system in Britain has led to the **new concepts of 'independent living' and 'direct payments'**. The movement has also created **participative and inclusive, 'user-led', services**, including Centres for Independent Living; housing agencies; employment agencies; community transport services; information, counselling and advocacy services, etc.

But it has been the fundamental philosophy of the Independent Living Movement which has influenced much of mainstream social policy, including post-1990 community care (Morris, 1993). This philosophy states:

- a) **that all human life is of value**
- b) **that anyone, whatever their impairment, is capable of exerting choices**
- c) **that people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives**
- d) **that disabled people have the right to participate fully in society**

So - some thirty years before community care legislation - disabled people were promoting concepts such as 'human rights'; 'choice'; 'control'; 'independence'; 'empowerment', within the context of social care.

### **Making Inclusion Work**

Most discussion in literature about the relative power relationships within decision-making processes has centred on the debate between 'Consultation' and 'Negotiation', which has its origins in the field of industrial relations.

Wall and Lischeron, (1977), for example, have said that consultation is not the same as negotiation. They term negotiation as an active process of demand and counter-demand, of statement and counter-statement, of influence and counter-influence. The

outcome of the negotiation process is one of collective responsibility for the joint decision. Therefore, the decision is one which all who participated in the negotiation can have some feeling of accountability and desire to make it work.

This is not the case for consultation. Unless the consultant has some esteem, or power over the consulter, they usually have little or no influence over the decision, which will be ultimately taken by the consulter. Subsequently, the consultant has significantly less responsibility for and accountability to the outcome of the decision. In terms of community care, the result for the consulter, i.e. the local authority, is the maintenance of power and prestige; and for the consultant, i.e. the user, alienation and disempowerment

Historically, the user has only had two weapons in his/her armoury to influence decision making within community care, neither of which has been totally satisfactory. He/she can become a nuisance to the provider or he/she, either alone or with others, can lobby politicians to advocate on their behalf.

The former is unsatisfactory because it often leads to the stigmatisation of the individual and sometimes even to the delivery of a service, which may be inappropriate and expensive.

Although the second is a basic civil right, it is unsatisfactory because it often leads to a compromise, which does little to change the fundamental power relationship between the provider and the user. The user remains disempowered, being outside the decision-making process, and, therefore, at the mercy of the provider. In reality, in order to have an effective influence in any decision-making process, the individual has to be present, or be represented when decisions are being made.

Drake (1992) has discussed this fundamental power relationship within decision-making in an article on 'disabled consumer' participation.

He reckons that if participation in decision making is to mean anything beyond tokenism or manipulation, then three pre-conditions to participation need to be fulfilled.

- a) **disabled consumers must have the capacity actually to exercise power (e.g., we must be able to make choices and understand the consequences of each)**
- b) **disabled consumers must occupy roles in which power can be exercised; we must have authority. (e.g., we must have control of the decision-making process)**
- c) **disabled consumers' role must be situated within links and networks such that the exercise of power is effective; that it achieves its purpose. (e.g., we must have the resources and personnel to carry out the decisions)**

According to Drake (1992), participation in service provision can only occur where disabled consumers have, acquire or develop the personal capacity to exercise power. Such a capacity involves, for example, an understanding of the options available to us in any situation and an ability to come up with our own, based on our own

experiences. Equally, disabled consumers need to occupy roles, which carry sufficient authority to allow power to be exercised. Rarely do mere advisory or consultative positions afford such authority.

Finally, pathways must be available through which authority may be used to put things into effect. The most effective way of implementing all three of these pre-conditions is to formulate a sovereign co-partnership agreement in both service planning and service provision.

Within the independent living movement this thinking has been apparent, when discussing service development and has led to the concept of 'Emancipatory Services' (Oliver, 1996).

### **Emancipatory services**

If society believes in the concept of full and equal citizenship for all, those both within and outwith the independent living movement who advocate 'emancipatory services' believe we must move from a system of dependency creating welfare to one of emancipatory services. The main pillars of emancipatory services are -

- ◆ **citizenship**
- ◆ **self-assessment**
- ◆ **self-management**
- ◆ **participation**

### **Citizenship**

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

**“ 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...”.**

'Citizenship' is, basically, the relationship between individuals and their societies. Many writers have argued that the welfare state has denied us many of our rights to citizenship in the fields of education, employment, housing, leisure and recreation.

After years of hard campaigning, the Government was finally shamed into bringing forward the Disability Discrimination Bill in 1995, which gave us certain limited civil rights. Very little evidence is available concerning the impact of the DDA on the quality of life of disabled people. Some are saying it is toothless, whilst others are relying more on the Human Rights Act. As it is, there is little or no case law to show disabled people have gained any great benefit from these pieces of legislation.

### **Self Assessment and Self Management**

Moving on to self-assessment and self-management, there is an interesting story by Dick Leaman, an activist within the movement, which neatly illustrates the issue of self-assessment and self-management. 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.

It has been said that social work '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 in local authorities, led by their prejudices and alliances.

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. '**

Yet many disabled people have been socialised into a feeling of disempowerment and dependency. Many may lack the knowledge and confidence to make a choice. Many under-estimate their needs. Most would rather not bother. But support for self-assessment and self-management is available from many peer group organisations. Peer involvement in self-assessment and self-management provides positive role models and develops empowerment, identity and social inclusion.

The NHS and Community Care Act policy guidance makes it clear that self-assessment and self-management should be integral to the care plan. Admirable concepts such as 'choice', dignity' and 'empowerment' - 'peer advocacy' even - but it is difficult to see any kind of compulsion being exercised to bring such concepts into reality.

## **Participation**

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

As Alinsky (1971) 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. .... 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. ...'**

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.

The adoption of this approach will also achieve best value, because the service will reflect the expressed need of disabled people within a framework of our raised expectations, as well as our conscious awareness of political and resource constraints.

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 (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 the 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 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 accompli*, merely for comment and discussion. The consultation process should be two-way. Those who wish real involvement of users need to listen to our agenda - at times and places suitable to us; and in a manner, or methodology, convenient to us.

### **Glasgow City Council Social Work Best Value Group:**

In an attempt to resolve these matters, a paper has been written as part of the corporate Best Value exercise in Glasgow City Council, to set out the Social Work Department's Framework for Consultation and Involvement with Service Users (Social Work Best Value Group, September 1998).

The Departmental Framework was written within the context of the City's corporate strategy on consultation. This states that consultation:

- ◆ Should be defined and the distinction between information, consultation and participation made clear
- ◆ Must be meaningful to all parties and not an endorsement of prior decisions
- ◆ Is a right and not a privilege
- ◆ Should be seen as core to the business of local authorities
- ◆ Should make clear who has access to the consultation process
- ◆ Should take place across all citizen groups
- ◆ Should recognise the rights of communities, such as gay and lesbian, to be consulted as a community
- ◆ Should be empowering and not disenfranchise those who are not members of groups and organisations
- ◆ Should take place at a variety of levels, with early involvement at planning stages as well as over specific issues and should recognise that different groups, organisations, agencies, individuals, may be required to be involved at different levels
- ◆ Should recognise the time and effort put in by organisations and individuals in the consultation process

Finally, the process of consultation itself should be subject to regular evaluation, review, and division, with particular attention given to how outcomes are communicated to all participants.

Glasgow's Social Work Departmental Framework acknowledged that user involvement would benefit from **“a more targeted, systematic approach where the relationship between different consultation exercises is clear, thus reducing the likelihood of service users being bombarded by consultations from a number of directions.”**

The Framework further states that fundamental to the entire process of consultation and the gathering in of information from citizens is the **“centrality of good quality information about services and processes to any consultation and participation strategy.”**

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 about services is also a crucial ingredient in all other forms of user participation in service development, not just consultation. It should be remembered that, 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

Glasgow's Framework lists the areas in which user consultation and involvement should be an integral part. These are

- ◆ Community Care Plans
- ◆ Users Strategy
- ◆ Commissioning Activities
- ◆ Service Plans and Reviews

Glasgow's Best Value exercise further establishes the importance of involving users in the critical stages of;

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

## **THE NATIONAL USER INVOLVEMENT PROJECT**

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 (Morris and Lindow, 1993). The National User Involvement Project was set up following this publication.

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. Details of these local projects were published by the NHS Executive (Morris, 1996)

Many of the points raised within the Social Work framework can be found in this report as well. For example, the facilitator of the Newham Project, Peter Ferns 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.

Morris (1996) gave 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. (*Section 46 of the 1990 National Health Service and Community Care Act*)

Within the field of disability service development, 'user involvement' is the engagement of disabled people in the decision-making of an amalgam of policy and service delivery activities, including planning, implementing and evaluating (Began and Fletcher, 1995)

Engaging disabled people in such decision-making not only improves the quality and appropriateness of the service, but 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)

Morris (1993) 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

She also argues that commissioners (i.e. within health and social services) 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).

In Part One of her book, Morris (1996) discusses the foundations and infrastructure necessary for user involvement. Here she gets to the kernel of the debate between consultation and involvement in decision-making. She asserts that there are three cornerstones to user involvement:

- ◆ Information
- ◆ Communication
- ◆ Decision-making

She 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. The development of the commissioning role, particularly in the context of tight budgets, requires a full knowledge of what best meets users’ needs and the involvement of users in promoting appropriate, effective services.”** (Morris, 1996)

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.

Before outlining the methods used by the National Users Involvement Project, Morris (1996) 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 us as equals. Equals with a valid and knowledgeable viewpoint. Equals with the same commitment to best value and high standards of service. The organisation's culture, the attitude of workers; the drive of senior managers; the commitment of politicians; all of these are necessary before user involvement in social work policy and practice is possible

As an aid, the Living Options project in Derbyshire drew up the following checklist to help managers assess their 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 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 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 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.

Bewley and Glendinning (1994) in a survey of the consultation processes within the community care planning of several English local authorities, made reference to the problem of the perceived lack of accountability of participating disabled people. Many social service managers had difficulty accepting the validity of the contributions made by representatives from the disability lobby, especially when they often seemed at variance with one another. On further investigations they discovered that there were different types of representatives of disabled people, each with their own (often conflicting) set of objectives, involved in the consultation processes.

This diversity of representation is the result of the ad hoc development of the voluntary sector in the vacuum of adequate, comprehensive and appropriate health

and social services. The plethora of representatives in the independent sector, each having their own agenda, include:

- ◆ Family members and other informal carers
- ◆ Well-known impaired individuals
- ◆ Voluntary organisations *for* specific impaired people (e.g. M.S. Society), run by informal carers and well-wishers (who may or may not employ professionals)
- ◆ Voluntary organisations *for* disabled people and covering general issues (e.g. Renfrewshire Council on Disability), run by informal carers and well-wishers (who may or may not employ professionals)
- ◆ Voluntary organisations *for* disabled people with a particular area of interest (e.g. a local swimming club), run by informal carers and well-wishers (who may or may not employ professionals)
- ◆ Service providers run *by professionals*
- ◆ Service providers run *by disabled people*
- ◆ Disabled people representing groups *of* disabled people.

Bewley and Glendinning (1994) found that those in the final category legitimately argued that they were more representative of the voice of disabled people, because they were accountable to a group of other disabled people and came armed with their previous deliberations.

It should be remembered that those called 'informal carers' (i.e. friends and family members) have their own unique needs, but these should not be confused with the needs of disabled people. The needs of informal carers should be considered separately from the needs of disabled people. Informal carers should not be asked to represent disabled people or disabled people's needs.

### **LIVING OPTIONS – PRACTICAL OPTIONS**

Begum and Fletcher (1995) have given a good outline of how such issues can be tackled in practical ways. After the International Year of Disabled People, The Prince of Wales Advisory Group on Disability set up the Living Options Partnership in 1985. This was an early attempt to unite local health, housing and social services authorities to work together to develop better services for disabled people. In various parts of England and Wales Living Options brought together representatives from these bodies to draw up plans and develop new and innovative services - a kind of precursor of Community Care Planning. Only here, the main catalysts were disabled people, themselves.

Ten years later, Begum and Fletcher (1995) looked at what had been achieved and drew together the basic principles and workings of these various projects for health and social service managers. In the final part of their paper they discuss similar issues to Morris (1995), namely:

- ◆ 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, the advice they gave is:

- ◆ 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 Morris' (1995) assertion that those users involved in planning should not only receive practical resources (e.g. transport, facilitation, meeting venues) but remuneration for their services, they also suggest:

- ◆ 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. Begum and Fletcher (1995) argue 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, they point out that user involvement will not see immediate effects and those who participate in it may get somewhat demoralised. In addition, as Morris (1995) says, some managers may see it as an end in itself, rather than a means to an end. It is therefore imperative that within any user involvement project there is an ongoing process of evaluation and feedback.

Unless the evaluation is managed sensitively, there could be difficulties with disagreements, competing priorities for all stakeholders and fears about the demands or expectations that may be placed on the different people involved. In particular, the views of disabled people are vulnerable and are liable to be marginalised. To avoid this Begum and Fletcher (1995) give some ideas:

- ◆ Agree at the outset basic ground rules, which incorporate the concerns of everyone involved and respect the skills and expertise of disabled people in a meaningful way. These ground rules should cover issues such as confidentiality, and dealing with disputes.

- ◆ Agree a timetable of work with tangible targets. This will need to incorporate short and long-term goals, so that all stakeholders know what they are trying to achieve.
- ◆ Be clear about what the initial aims and objects are and why a certain type of approach was adopted.
- ◆ Review the achievements of any work and identify outcomes.
- ◆ Set up a meeting, training or review forum to come together once every six or twelve months to discuss how well user involvement is working, to identify future priorities and to explore alternative options if there are difficulties.

In Part Two of the book by Morris (1996) she describes different types of approach to user involvement, discussing within each their advantages, disadvantages and things to think about when attempting them. She describes local projects within the National User Involvement Project, which adopted the approach. In Part Three she also gives checklists for user involvement. Information from both of these parts of her book is too detailed to replicate in this paper. However, the methods of user involvement, outlined, are listed below:

- ◆ 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)

On 13<sup>th</sup> April 1994, Living Options Partnership held a seminar, 'Promoting User Involvement: Ideas into Action'. The aims of the seminar were

- ◆ to help Living Options Partnership Network Areas clarify their thoughts on user involvement;
- ◆ identify some of the factors, which hinder its success and conversely,
- ◆ enable it to happen; and
- ◆ consider some of the key issues and appropriate methods of involving users in specific types of service. (d'Aboville, 1994).

As with Morris (1996) and Begum and Fletcher (1995) the seminar covered roughly the same spectrum of user involvement:

- ◆ **Providing information** – how and where decisions are taken and by whom? What services are available and how else could needs be met?
- ◆ **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.
- ◆ **Delegated control** – where statutory agencies delegate control over key decisions or services to individuals or user-led organisations

Discussions centred around:

- ◆ What the different types of user involvement can achieve
- ◆ What their limitations are
- ◆ What factors get in their way of success (blockers)
- ◆ What can be done to overcome them (unblockers)

Like Morris (1996) instances of where each type of user involvement was operating were provided, alongside the discussion. Again, there is too much information to repeat in this paper. However, I have a handout of a synopsis of the different types of user involvement, what they can and cannot achieve and each ones 'blockers' and 'unblockers'.

### **Multi-discrimination**

Before summarising this paper, it would be remiss of me not to discuss the issue of multiple discrimination. The involvement of black and gay disabled people has not been highlighted much in the preceding research work.

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.

Begum (1995) clearly set out the issue for black disabled people, which could also be said for gay disabled people - and, to a lesser extent now-a-days, disabled women. The specific needs of black disabled people are not met by services for white disabled people, or for black non-disabled people

The other issues emerging from research are:

**Invisibility** - It difficult to reach black disabled people because they are absent from networks of disabled people and black people. Therefore they are at greater risk.

**Multi-discrimination** - It is problematic to describe people as 'double', or 'triple' discriminated. Black people - like gay people - cannot separate different aspects of their identity and allocate them to different pigeonholes. Discrimination on the grounds of race, disability and sex operates and interacts in different ways and impinges on the lives of black, white: homosexual, bisexual, heterosexual; female, male disabled people in each and every individual way.

**Racism** - 'Institutional' racism is more difficult to overcome than 'direct' racism.

**Disablism** - It is racist to believe that black communities are any more negative towards disabled people than white. Disablism occurs within both.

**Low levels of take up** -The idea that 'They take care of their own' has maintained the inertia to seek the involvement of black disabled people, even as users of the service. Many black disabled people appear to be struggling without much support from statutory or voluntary services.

As a practical piece of participative action research, the Council of Disabled People Warwickshire, with the assistance of the Centre for Social Justice at Coventry University, developed ways to involve black disabled people in their organisation. Here is just a summary of the strategies and action plan the research with which the research concluded (Evans and Banton, 2001):

### **Strategies for involving black disabled people**

- ◆ Provision of good physical access, a comfortable venue and transport to encourage opportunities for black disabled people to be involved in consultation, evaluation and policy development.
- ◆ Flexible models of work to allow black disabled people to make choices about issues like the role of the family and whether they use separate and/or mainstream services. The goal should be to make all mainstream services accessible, inclusive and encompassing of diversity.
- ◆ Before beginning on practical work, 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 that supports different types of involvement and movement between them

### **Action Planning**

Finally, the Council Of Disabled People Warwickshire suggest an effective action plan for developing the involvement of black disabled people should include joint agency work, realistic target setting, race and disability training for staff and regular consultation and evaluation with black disabled people.

To get work started, the Council also suggest, organisations may best use limited funds by employing a black worker, training their staff, consulting with black disabled people about their needs or undertaking some direct work.

They conclude, the most effective way to speed things up would be through joint agency work and the sharing of good practices.

### **SUMMARY:**

To summarise - user involvement in disability services must:

- ◆ Be composite in nature.
- ◆ Vary according to the nature of the task and participants

The general aim of 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)

The outcomes of user involvement should be:

- ◆ 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.

The areas in which user involvement should be an integral part include:

- ◆ Developing community care plans and service strategies
- ◆ Setting service standards
- ◆ Developing service specifications
- ◆ Assessing service performance
- ◆ Reviewing service performance
- ◆ Agreeing action for continuous improvement
- ◆ Service planning / performance planning
- ◆ Finding out what is needed (new ideas)
- ◆ Writing contract specifications
- ◆ Inspecting services
- ◆ Appointing staff
- ◆ Being on management committees
- ◆ Being on commissioners' forums
- ◆ Writing and monitoring complaints procedures
- ◆ Assessment procedures and processes

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

There must be an adequate infrastructure for user involvement, including the provision of:

- ◆ Adequate training to overcome the assumptions and anxieties of commissioners and provide them with the relevant skills, understanding, and experience
- ◆ Adequate budgets for information, transportation, facilitation and remuneration
- ◆ Service users and their organisations with the relevant knowledge, skills, and resources
- ◆ Training to those who facilitate user involvement at meetings, etc, about what needs to be achieved
- ◆ Continuous evaluation of user involvement projects themselves
- ◆ Continuous feedback to users of the outcomes from these evaluations, as well as the suggestions for new services

This paper has postulated some ideas to develop a strategy for the implementation of a programme of user Involvement projects. This strategy 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 our real needs and therefore will meet the criteria of best value more closely. It is also predicted that the disabled people who participate in the user involvement programme will identify with the service more closely and feel some accountability and responsibility for them. In addition, it is hoped more of us 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, 1996)

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