Empowerment and Self Advocacy

Introduction

The aim of this session is to explore the concept of empowerment in the context of working with people who have a learning disability. Empowerment is not a recent idea, and has been used in a variety of different ways - some of which are inappropriate (Gilbert, 1995).

Definitions of empowerment include the following:

- Enhancing the possibilities for people to control their own lives (Rappaport, 1981)
- A process by which individuals, groups and/or communities become able to take control of their circumstances and achieve their own goals, thereby being able to work towards maximising the quality of their lives (Adams, 1990)
- A process of helping people to assert control over the factors which affect their lives. It involves a transfer of power from the professional to the patient - nurses and other health care professionals need to give up their power and help their clients gain power (Gibson, 1991)
- It involves giving more power to users over decisions, and hence it probably involves taking power away from service providers (Taylor et al 1992)
- Empowerment is not a process by which those in society who have power can dispense some to those who don't have any, but implies a process in which people with learning difficulties *take* some control over what is happening (Simons, 1995)
- The process by which individuals, groups and or communities become able to take control of their circumstances .... The emphasis being on power being *taken* and its use determined by the goals of its possessor (Jack, 1995)

Power and Empowerment

Power is a scarce commodity in that not everybody has it. As a result, there are tensions between those with power and those without power. Those with power tend to resist giving it away and those without it tend to seek more power for themselves.
Think Point

Think of someone you know who you feel is powerful. What attributes do they possess to make you feel that they are powerful?

How do you feel in the presence of this person?

What do you think makes you feel this way?

People can experience power positively or negatively. For example, consider the issue of confidential References. If your previous employer wrote a reference for you in confidence and you did not know the content of the reference you may feel that you have been disempowered by the lack of knowledge, and unprepared to face questions from a potential interviewer. You would more than likely experience this power negatively. If however your previous employer gave you an indication of the content of the reference, being in possession of knowledge about yourself would result in experiencing the power more positively.

When you experience power negatively, you feel powerless. Powerlessness is a state where individuals hold an expectancy that their own behaviour will not/cannot effect or determine access to the resources or opportunities they desire. The effect of powerlessness on a long term basis leads to the individual no longer considering such opportunities - they accept the condition as being natural and beyond change. There are feelings of alienation and distrust.

Think Point

Think of someone you know who has a learning disability in relation to power and powerlessness. How much power do people with learning disabilities hold?

Historically, people with learning disabilities were cared for in institutions. As a result, a process of institutionalisation took place:

Institutionalisation is a process by which patients lose autonomy and function completely and are dependent upon the institution in which they live. Patients learn to conform to the rules and routines of the institution. They will lose their old self and obtain a new, institutionalised identity (Goffman, 1961)

Institutionalisation also includes:

- loss of contact with the outside world
- enforced idleness
- brutality, violence, bullying, harshness, browbeating, teasing and tormenting
- bossiness of staff
- loss of personal friends, possessions and personal events
- ward atmosphere which is not conducive to normal living
- loss of prospects outside of the institution

People with learning disabilities became institutionalised because of the power of those who worked in institutions

**Empowerment in a Social & Political context.**

The relationship between professionals and service users is central to the empowerment debate. Skelton (1994) stresses that the roots of the concept lie in the political interpretation of the relationship between the individual and authority. Empowerment, according to Jack (1995) is all about power and the defence of sectional interests - professionals are not simply involved in debating which technique to employ in the interests of service users, but are also involved in defending their own interests. Katz (1984) suggests that the problem of empowerment arises from the nature of westernised society. People are unwilling to practice empowerment as it means that there will be a redistribution of power from the powerful to the powerless.

It has long been argued that most nurses lack the power and authority required for empowerment (Miller et al, 1983) because of the power influences that inhibit the growth of individuals in the profession, namely the Bureaucratic power of the health service organisation, the medical profession and also the restrictions that the nursing profession itself imposes on nurses in the form of codes of conduct, nursing policies and procedures.

Field (1980) states that in order to have the authority to empower a patient or client, nurses should have three areas of power invested in them:

- Personal power (be a competent practitioner with confidence and self esteem)
- Invested power (given to individuals who place their trust and confidence in an institution)
- Delegated power (power given to the individual which is perpetuated in policies, rules and regulations - recognised in the job description)
Think Point

- Think of a situation where you or a colleague attempted to empower a client. Were you or your colleague successful in empowering that individual?

- If not, were you lacking in any of the areas of power identified by Field?

- What do you feel was the model for care provision at the time - Bureaucratic, Para-medical or Professional?

Nurses constantly work within these conflicting ideologies and have to balance the amount of power they hold against the power that they can give away. The balance of power between the patient and the nurse is influenced by the role which the nurse adopts. The traditional caring role of the nurse may disempower patients/clients by creating a parent-child relationship. This relationship may develop as a result of the hierarchical and bureaucratic model of care provision and a fear of neglecting patient/client needs through taking risks in care provision.

The nurse when in empowering mode, will function as a non-directive facilitator supporting the patients choices (Elliot & Turrell 1996). In its strictest sense, this could require the nurse to function purely to empower the patient or client, taking risks and rejecting policies, procedures, rules, regulations, codes of practice etc. in favour of empowering individuals to uphold their rights. As Simons (1995) warns, "supporting service users in their attempts to challenge the system will inevitably create conflicts of interest for professionals"

Chavasse (1992) argues that before nurses are in a position to empower clients, they must empower themselves - ie assert themselves in the health care division of labour where nurses are subservient in position. As Evans (1992) notes, there is a basic contradiction in the idea of people empowering others because the very institutional structure that puts one group in a position to empower, also works to undermine the act of empowerment.

Jack (1995) also points out, the notion that professional providers of services can empower service users in the sense of giving power to them is paradoxical. Power cannot be given, but only taken, for "to give power implies a gift from a position of power". Jack (1995) warns that this will continue until the institutions change or the user creates their own service which they control - both of which require political action by citizens rather than therapeutic intervention by professionals

Despite this paradox however, empowerment in the context of working with people who have a learning disability has become increasingly popular. This
popularity is partly due to the benefits associated with patient empowerment (Elliot & Turrell 1996).

**Micro and Macro Levels of Empowerment**

Malin and Teasdale (1991) distinguish between two levels at which empowerment can be practised - the Micro Level and the Macro Level. They suggest at the "Micro" level, nurses place their skills at the disposal of the patient/client and trust their patient/client will make responsible decisions. Malin and Teasdale (1991) view the organisational and management actions to be the "Macro" Level of empowerment. They do warn however, that both levels have constraints. At the Micro level, nurses are subject to constraints from nursing managerial and medical hierarchies, and at the Macro level, organisations are subject to constraints from Governmental policies and Treasury decisions.

**Empowerment in Practice**

In the field of learning disabilities nursing, the concerns regarding "quality" in care has focused on the concept of normalisation and rights for service users. In this context, the emphasis on empowerment is to facilitate the access of personal responsibility and choice on the part of the client, and is seen to have therapeutic as well as political ends (Skelton, 1994). However, as McConkey and McGinley (1990) warn, once an activity has been labelled as a therapy, the professional takes control. If empowerment is then regarded as a therapy, it would nullify the ethos of empowerment and become an enabling process rather than an empowering process. As Jack (1995) notes, enablement is about developing capabilities and is a professional skill, empowerment is about the struggle for power and control and is essentially a political activity.

Mullender and Ward (1989) are also very sceptical of the use of empowerment in professional practice and suggest that empowerment has the effect of placing practitioners in a position where they cannot be challenged or criticised:

**Empowerment is used despite the fact that it masks inherent tensions. It acts as a social aerosol covering up the disturbing smell of conflict and conceptual division. It is being used to protect professional practice from scrutiny (Mullender and Ward, 1989)**
A Staff Nurse was questioned during a Quality Audit as to why a particular client was never given any fruit or vegetables and answered "It is his choice, he doesn't want them".

The staff nurse used the concept of empowerment to rationalise not dealing with the situation appropriately and avoiding a confrontation with the client regarding his diet. What should have been done in this situation?

To have power is to be able to influence events. Simons (1995) notes that although few people feel powerful, most of us have some power: as individuals (by virtue of skills or experience), through our relationships and through the groups and organisations we belong. For people with learning disabilities, empowerment means having access to the same kinds of mechanisms, enabling them to gain some influence over the world around them and to have at least some control over their lives.

**Assertiveness and Empowerment**

Developing assertiveness skills is necessary in empowerment. Despite this fact, the training that is generally provided by services constitutes compliance rather than assertiveness (Simons, 1995). Ironically, while there is evidence that at least some of the anger and frustration underlying "challenging behaviour" is provoked by the lack of control people have over their lives, the response to that anger is often to reduce people's autonomy further! One way of breaking out of this cycle is to help people acquire the skills of asserting themselves without having to resort to aggression.

Discuss how would you provide an opportunity for people with learning disabilities to access assertiveness courses?

**Self Advocacy and Empowerment**

The Self Advocacy movement is about collective empowerment. As Simons (1995) notes, one of the most liberating experiences for many users is to discover that they are not alone, that there are others in a similar position. However, it is important that professionals do not set out to control the form and agenda of self-advocacy groups. Advocacy, of all kinds, is about acquiring a voice. It is difficult to imagine being empowered without being heard. Advocacy and empowerment are therefore inextricably linked. However, to behave in ways that are empowering implies a commitment not just to listen to people with learning difficulties, but to act on what they say.
Even with good intentions, positive initiatives can be undermined by the subtle signals sent to people with learning disabilities - for example, when professionals insist on teaching service users about self advocacy the subtext is "we are still the experts, we know what is best for you". As health care providers, it is not possible to know what is best for service users. As Anderson (1989) notes:

the difference between the provider of health services and the patient resembles that between the hen and the pig in the preparation of eggs and bacon. The hen is involved but the pig is committed (Anderson 1989).

The skills required to help people decide what they want and make informed choices are different to those involved in telling people what their needs are.

Having a voice is essential in empowering people within the health care system, but there are still many groups within the NHS who deny that patients/clients have a legitimate right to a voice (Cooke, 1994). People with learning disabilities are as diverse as any other group of people. They have widely varying attitudes, skills, experience and interests. Not everybody will want to join a self-advocacy group. A range of options for people to get involved will therefore enable people to find the niche in which they are most effective or with which they feel most comfortable (Simons, 1995).

**Think Point**

Identify a range of options that might be available for people with learning disabilities to voice their concerns regarding the health care system

**Concluding Comments**

To conclude this session, it is worthwhile to reflect on these comments extracted from Simons (1995)

Empowerment is not a process "by which those in society who have power can dispense some to those who don't have any (Oliver 1993). By definition, empowerment implies a process in which people with learning difficulties take some control over what is happening. However, that does not absolve professionals from the responsibility to use all the means at their disposal to aid that process

For a strategy to work, professionals need to be self-critical as well as being prepared to make links, to generalise from specific situations and to draw out the wider implications of events.
There is a need for structures to adapt to people with learning disabilities. There is an almost unconscious assumption that people need to be prepared or need to have acquired skills before they can participate, as though participation were a reward rather than a right. If people with learning disabilities find it hard to use a particular structure, then the solution lies in changing the structure not the people - it does not mean business as usual simply with a few users present.

On a final note, Dawson (1997) highlights a more positive attitude towards empowerment for people with learning disabilities:

Participation does not simply occur because it is 'good practice' or as a result of a maveric manager's idea. As a non-tokenistic objective it needs commitment and allocated resources. People using services often need oppurtunities and skilled support in order to learn how to speak up for themselves and effectively take part in meetings. In turn, nurses, social workers and day service officers must learn to listen and encourage this. Services are there to empower and value people and participation in service planning is seen as a means to a new beginning for people with learning disabilities.


DAWSON, P. (1997) Service Planning and people ,with learning disabilities, British Journal of Nursing, Vol 6, No 2, Page 70


