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CHAPTER 7

User Empowerment and Community Care

Chapter summary

This chapter:

- Discusses some key influences on empowerment in community care including the independent living movement and direct payments; the social model of disability; normalisation, ordinary living and person-centred planning; the self-help and user movement; and community development.
- Outlines two models of empowerment and describes a 'ladder of empowerment'.
- Situates community care in a wider context and considers debates on social exclusion and regeneration.

Introduction

Previous chapters have referred to the recognition of user empowerment in the community care changes of the 1990s. It has been pointed out (for example, in Chapter 4) that this has often conflicted with other objectives, including the rationing of services and the provision of services within tight budgets. This chapter explores the welcome emphasis on empowerment, but this needs to be considered in the wider context that includes the often complex and varied expectations that practitioners have to meet. User involvement can be applied to all situations of community care in some way. As an illustration, Box 7.1 mentions a study where it is applied to people who are seriously ill.

Box 7.1 User empowerment and seriously ill people

Issues of user empowerment apply across the whole range of situations covered by community care. A study called *Too Ill To Talk* (Small and Rhodes, 2000) assessed the concept of user involvement in services for people who suffer from multiple sclerosis, motor neurone disease and cystic fibrosis. Some issues that I drew from it were:

- User-involvement is important across the whole range of services dealing with living and dying.
- The importance of retaining some control over the process of dying and death. There may be issues about choice of place of death. Euthanasia is not legally acceptable in United Kingdom but some influence on the process of dying may be important to the patient.
- The research study had the notion of people leaving a legacy by influencing services for others after they had died.
- The importance of recognising that some people living with a serious illness may have more pressing concerns and may actively choose not to take part in user involvement.

One of the three fundamental aims of *Caring for People*, was to 'give people a greater individual say in how they live their lives and the services they need to help them to do so' (DoH, 1989a, p. 4). Later practice guidance from the Department of Health further emphasised involving service users and increasing their choices. The language of empowerment is employed to promote this objective:

> 'The rationale for this reorganisation is the empowerment of users and carers. Instead of users and carers being subordinate to the wishes of service providers, the roles will be progressively adjusted. In this way, users and carers will be enabled to exercise the same power as consumers of other services. This redressing of the balance of power is the best guarantee of a continuing improvement in the quality of service.' (DoH, 1991a, p. 9)

The aspects of user empowerment that were built into the community care changes of the early 1990s can be summarised as follows:

- Users were to receive better information about services and procedures.
- Each social service authority was required to set up a complaints procedure for users.
- There was to be consultation with users in relation to community care plans.
- Assessment of individuals was to be guided by the needs of the user.

Although the changes were useful in themselves in practice they only had a limited impact on empowerment. The empowerment envisaged was mainly strengthening the individual's right to (1) complain, (2) better information and (3) needs-led assessment. The scope for collective organisation was limited to participation in community care plans and whatever could be made of the general rhetoric of user empowerment.

It is clear that there was only limited government encouragement of user empowerment. Since then a variety of other influences on community care have had a greater impact on real empowerment. Foremost among these are:

- The independent living movement and direct payments.
- The influence of the social model of disability.
- Ideas about normalisation, ordinary living, and person-centred planning.
- The continuing development of the user movement and self-help groups.
- The influence of community work ideas and practices.

There has been an interlinking of these influences so that they have all had an impact on each other in different ways. The first five sections of this chapter will outline each of these influences in turn. What follows however cannot show the complexity of this interlinking or the detail of the debates that have taken place. All of them have contributed to the development of good practice. It must be remembered that practitioners have also had to struggle with resource constraints, which frequently serve to limit empowerment.

Independent living movement and direct payments

In the United States during the 1960s, discrimination was identified as a major problem in relation to black people, women and disabled people. Disability thus became an issue of concern to the civil rights movement. The links between oppressed groups were made more explicit in the United States than in the United Kingdom. The movement of disabled people in the United States has sometimes been called the Independent Living Movement and there have been examples of disabled people taking service provision into their own hands, for instance the first Center For Independent Living was set up in Berkeley, California, in 1972 (Crewe and Zola, 1983). Other centres were opened during the subsequent years. A central aim was to 'demedicalise' disability, that is, to put a stop to disability being treated as akin to sickness.

The movement has been slower to develop in the United Kingdom. It had its origins in people's attempts to leave residential care and live independently in the community. Examples of important initiatives are the Derbyshire Centre for Integrated Living, the Hampshire Centre for Independent Living and the West of England Centre for Inclusive Living. The Derbyshire Centre for Integrated Living was set up in the early 1980s. It was run and managed by disabled people for disabled people with a mission is to secure independent, integrated living opportunities for disabled people in order to promote their full participation in the mainstream of economic life in Derbyshire. Further details of its history and development can be found in Priestley (1999).

Box 7.2 Centres for independent living

The Prime Minister's Strategy Unit's report *Improving the Life Chances of Disabled People* (2005), reported that there were 22 fully constituted centres for independent living (CIL) and another 15 local disability organisations either providing a similar role or working towards becoming such a centre. For most CILS, their main activity and source of income is running support schemes to assist and enable disabled people to use direct payments.

According to Jenny Morris (1993), the philosophy of the independent living movement is based on the following assumptions: that all human life is of value; that anyone, whatever their impairment, is capable of making choices; that people who are disabled by society's reaction to physical, intellectual and sensory impairment and emotional distress have the right to assert control over their lives; and that disabled people have the right to participate fully in society (ibid., p. 21).

Independent disabled people (as in the independent living movement) argue that they are in charge of decision-making even if they do not do all the tasks themselves (for example, getting washed and dressed). The reversal of the power relationship is achieved by moving away from disabled people being controlled by personal assistance (however kind and well-meaning) towards control over the type and timing of the personal assistance they receive. That is, disabled people themselves decide which services they want (such as help with getting up, going to bed, eating) and when they want them. The physical inability to do certain tasks should not lead to loss of control and choice. What is important is the nature of the relationship with the person who is doing the tasks. This relates to who is in charge of what is done, how it is done and when it is done. Obviously there can be tensions between this philosophy and the way in which caring has been done in the past by many carers – both formal and informal. This potential and real conflict was brought out at the end of Chapter 2 and practitioners may experience conflicting pressures between the aspirations of disabled people and the concerns of carers.

The setting up by the UK government of the Independent Living Fund (ILF) in 1988 gave a boost to the independent living movement. Disabled people who could meet the assessment criteria were given a regular grant that enabled them to employ people to help them live independently. Hence, the fund gave disabled people control over their own care by enabling them to employ the carers of their choice and tell them what to do. This was very different from having to accept the dictates and organisation of the local home care and nursing service. Power shifted to the disabled person. In this way, the fund fed into the aims of the Independent Living Movement and provided a vision of how user-led and user-controlled care packages could be set up to meet the real needs of disabled people.

The closure of the ILF in its original form in 1993 provoked a great deal of anger among disabled people as it had provided them with greater control over their own lives as well as independence, and for many its removal meant a real reduction in possibilities for empowerment. During the early 1990s, there was a lot of pressure on the government by organisations of disabled people to legislate on direct payments and this pressure eventually bore fruit with the passing of the Community Care (Direct Payments) Act 1996.

Direct payments (DPs) is the system in the United Kingdom where individuals are given the money to chose and pay for their own social care rather than have directly provided services. Employing and directing personal assistants has always been central to the notion of direct payments. They are a means by which disabled people and older people can maintain control of their lives and there is a developing literature on what needs to be in place to enable it to work (Hasler and Stewart, 2004).

There have been concerns about the implementation of the policy. A report by the English Commission for Social Care Inspection (CSCI) in 2004 recorded the low take-up of direct payments and the great variability between authorities. The CSCI noted that since April 2003, English councils had been required to offer direct payments to anyone using community care services who could consent to the scheme. The report suggested that a combination of incompetence, lack of information, patronising attitudes and unhelpful paperwork had stalled the direct payments changes.

While there is a remarkable consensus on the merits (and contribution to empowerment) of independent living and direct payments, it is necessary to maintain some critical perspectives. Spandler notes how there are elements of various strands within DPs. She writes, 'The history of DPs has therefore comprised a complex confluence of new right, New Labour and welfare user movement ideologies and demands' (2004, p. 190). In an overview of the positives and the negatives of DPs, Spandler (2004) cautions that a number of factors need to be addressed in order to ensure DPs continue to be a progressive strategy. Such an individualistic approach could undercut collective notions of provision. Direct Payments might also lead to greater privatisation and there can be concern about the rights and conditions of workers under direct payments schemes (ibid.). Another writer has suggested that there may also be dangers of governments using this provision to cut back on other programmes and to increase pressure on families to look after their elderly relatives (Oldman, 2003). One study suggested that DPs might be a way of creating a more integrated and seamless service for people while at the same time contributing to the shift of funding responsibilities from health to social care (Glendinning *et al.*, 2000). Scourfield (2005) endorses the principles underlying DPs but raises questions about whether there will be an adequate supply of personal assistants and considers some of the concerns in relation to personal assistants around risk, training and regulation. This intriguing and important debate will go on – not least because the English government's Green Paper on adult social care (DoH, 2005b) clearly envisaged a much more central role for DPs within welfare provision in the future. This was confirmed in the subsequent White Paper (DoH, 2006).

Discussion about DPs has merged into discussion about 'individual budgets'. Take up of DPs was somewhat disappointing and it is acknowledged that some people and some groups do did not wish to have the burdens associated with them. Becoming an employer and taking on these responsibilities are very real barriers for many people. Both the Green Paper (DoH, 2005b) and the White Paper (DoH, 2006) discussed 'individual budgets' as a way forward that would reduce these barriers. The 'individual budget' would be held by the local authority on behalf of the service user. By this approach some resources are allocated to an individual based on an assessment of their individual need. Service users with individual budgets could ask councils to hold and administer payments for them. Service users can also buy council run services with their personal budgets, which they cannot do with DPs. Support is provided to help the person decide what they want and they can choose to receive support by the provision of services or by way of a cash payment. A number of pilot projects were to test out the way forward. In many situations practitioners would be less care managers but more navigators, facilitators or brokers.

The social model of disability

People involved in the independent living movement have often used the social model of disability as a theoretical perspective. The two influences on empowerment are intertwined. As one example, the Derbyshire Coalition for Inclusive Living says that its action programme is based on a social model of disability. What does this mean?

A model is a simplified version of how things operate and can help make sense of a complicated situation. Two models can be used to explain how disability is regarded by society. The first is the 'individual model', in which a disabled person is seen as having to adjust to society. (This model is sometimes called the medical model, the traditional model or the personal tragedy model.) Central aspects of this model are that disability is viewed as a 'tragic' situation; individuals have to adapt to their impairment; individuals have to adapt to fit into society; and disabled people may be seen as either objects of pity or heroes (Oliver and Sapey, 2006).

In contrast, under the 'social oppression model' society is expected to adjust to the disabled person. This model is advocated by a number of disabled persons' organisations and writers (e.g., Oliver 1990, 1996). From this perspective disabled people are seen primarily as an oppressed group, prevented from achieving their full potential by the structures of society and the language and belief systems which society develops about disabled people and their lives. Society 'disables' individuals both by creating environmental obstacles and by its attitude towards them. For example, disabled people have the same range of needs and feelings as other people but society restricts their access to public transport, entertainment and public places as well as education and employment. According to this approach, action should be taken to enable disabled people to play a full and equal part in all aspects of life.

These two models simplify complex situations but they nevertheless have fundamental implications for disabled people, their carers and the organisation of services provided for them. The model adopted will affect how practitioners behave and the way in which they practice. It is probable that most people have been heavily influenced by a portrayal of disability that conforms largely to the first model and is constantly reinforced by the media and some charities.

The social model does not stress the restrictions created by impairments, but rather the restrictions created by a society geared to able-bodied people. It shows how society denies disabled people the means to do what they are capable of doing. Hence, the problem is not the impaired individual but the disabling society. This model emphasises the need to identify the way in which the structures and institutions of society further disable people with disabilities so that these disabling structures can be challenged. The social model celebrates difference and has related in the past especially to people with a physical or a sensory impairment.

Proponents of the social model have been critical of those involved in the 'rehabilitation' services for medicalising the rehabilitation process

(Nocon and Baldwin, 1998). Health and social care workers in rehabilitation services have had to rethink their practices as a result of these criticisms. This also applies in respect of the influence of the ideas of normalisation.

Normalisation, ordinary living and person-centred planning

Normalisation has been especially influential in relation to services for people with learning difficulties, an area of provision in which the social model of disability has had only a limited impact (Stalker *et al.*, 1999). In the past people with learning difficulties were often shut away in large hospitals as a result of policies of physical exclusion and segregation. The ideas of 'normalisation' grew as a way of combating segregation and integrating people with learning difficulties back into society. Its origins were in Denmark in the late 1950s and the ideas influenced the provision of services in Denmark and Sweden in the 1960s. In the United States, during the 1970s and the 1980s, Wolf Wolfensberger (1972) proposed and then developed more elaborate ideas on normalisation, which he later referred to as 'social role valorisation'. This is his preferred description but the word 'normalisation' is still commonly used.

The aim of normalisation is simply to treat all people as equal citizens, with equal rights and equal access to valued social roles. The ideas of normalisation are applied to groups of people who have been regarded as of lesser value and suggest how to change that situation. Members of such groups are likely to be treated unfairly and unjustly, thus discrimination is one consequence of being devalued.

A vicious circle can be set up in which people who are seen and treated as being of lesser value come to believe it themselves. That is, when people hear negative views about themselves and experience negative behaviour, then over time they come to accept that view of themselves. Another word for this is 'internalisation'. Normalisation is one tool for identifying, analysing and breaking the circle that traps various groups of people into maintaining poor views of themselves and discourages their aspiration to be valued members of society. This can happen to people who are elderly, people who have a physical, sensory or learning disability and people with mental health problems. Thus the ideas of normalisation are relevant to all adult groups in the field of community care.

Normalisation principles have been a force for change in the United Kingdom, and in particular they have contributed to the 'ordinary life' movement. This movement is based on the conviction that people with severe learning difficulties should live ordinary lives. John O'Brien (King's Fund Centre, 1991) has described the implications of normalisation in relation to what services should try to achieve or accomplish for users. He has identified five major service accomplishments that are a practical application of the 'ordinary life' values for people with learning difficulties (ibid., p. 45):

- Community presence: the right to live and spend their time in the community rather than in residential, day or leisure facilities that segregate them from other members of society.
- Competence: in order for a full and rewarding life to be lived in the local community, many will require help with learning new skills and gaining access to a wider range of activities.
- Choice: a high-quality service will give priority to enhancing the choices available to people and generally protecting their human rights.
- Respect: services can play an important role in helping people to enjoy the same status as other valued members of society.
- Relationships: help and encouragement are needed to enable people with learning difficulties to mix with other non-disabled people in their daily lives.

These have been powerful and radical principles when applied to much of the provision which has been available for people with learning difficulties. Since the 1970s, people with learning difficulties have progressed towards living ordinary lives in a whole variety of areas, such as education, housing, employment and leisure. To use a more recent term, normalisation has acted as a powerful tool against social exclusion.

According to some interpretations of normalisation the devalued group is expected to adopt the culture and lifestyle of the dominant group (this process is sometimes called assimilation). However, while oppressed groups want to be valued as human beings, they might not wish to follow an approach that sees assimilation as the only goal or assumes that disadvantaged groups should aspire to society's norms (Szivos, 1992, p. 128).

In summary then, whereas the social model acknowledges and celebrates difference, normalisation has often appeared to emphasise assimilation. Szivos suggests that at a practical level, health and social care workers might ask themselves whether their way of working improves 'the self-concept of [the] client by acknowledging his or her right to feel positively about being different?' (ibid.)

Various White Papers and strategies have been published to further inform and guide practice. In England, *Valuing People* (DoH, 2001b), was published. *The Same as You* (Scottish Executive, 1999b) was published in Scotland and *Fulfilling the Promises* (Learning Disabilities Advisory Group, 2000) was produced in Wales. In many policy documents, the previous language of normalisation, social role valorisation and ordinary living has often been replaced by the language of 'person-centred approaches' – approaches that are intended to enable people with learning disabilities as much choice and control as possible over their lives. Mansell and Beadle-Brown write, 'Person-centred planning is an approach to organising assistance to people with intellectual disabilities. Developed over nearly 30 years in the United States, it has recently assumed particular importance in the United Kingdom because it forms a central component of the 2001 White Paper *Valuing People*' (2004).

The two sets of guidance associated with the English White Paper both had 'person centred' within their titles (DoH, 2002a, 2002b). In this guidance, the Department of Health defines person centred planning as, 'a process for continual listening, focusing on what is important to someone now and in the future, and acting upon this in alliance with family and friends' (2002b, p. 12). The guidance acknowledges different planning styles and planning tools and that these can be used for the process. It stresses that there are five key features that help to distinguish it from other forms of planning and assessment. These are outlined in Box 7.3.

Box 7.3 Five key features of person-centred planning

The following five features are said to distinguish person-centred planning from other forms of planning:

- 'The person is at the centre.
- Family members and friends are full partners.
- Person-centred planning reflects the person's capacities, what is important to a person (now and for their future) and specifies the support they may require to make a valued contribution to their community.
- Person-centred planning builds a shared commitment to action that will uphold the person's rights.
- Person-centred planning leads to continual listening, learning and action, and helps the person get what they want out of life'.

(DoH, 2002b, pp. 13–14)

This is a developing area of policy and practice with ongoing debate as to whether it will deliver what it intends (Mansell and Beadle-Brown, 2004). The Department of Health guidance (DoH, 2002b) is a source of further information and Ritchie *et al.* (2003) have produced a helpful practical guide for would-be implementers of person centred planning. The language of 'person-centred' and 'person-centred planning' is also used in relation to other users of community care service users (DoH, 2001c).

The growth of self-help groups, user groups and movements

There is a long history of self-help and self-organisation among users of community care services. The British Deaf Association was formed in 1890 and the National League of the Blind was set up as a trade union in 1899. This rich history can be explored in works such as 'Disability Politics' (Campbell and Oliver, 1996). A number of writers describe this history in terms of the development of a social movement (Beresford, 1997; Campbell and Oliver, 1996; Priestley, 1999). Some disabled people see it as a liberation movement (Oliver, 1996). The disability movement has been greatly influenced by the social model of disability and the idea of independent living, and the two have become inextricably bound together.

While the history of self-organisation goes back a long way (Campbell and Oliver, 1996), there has been considerable growth of disabled people's and service users' groups since the 1970s (Beresford, 1997). The growth and development of the independent living movement was discussed earlier in the chapter. There are numerous lessons to be learnt from the growth of self-help and user groups. Organisations have usually followed the principles and values of community development by emphasising collective organisation and self-organisation. The concept of community has been based on a 'community of interest' rather than a geographical area, but it nonetheless utilises the principles of community development. Self-advocacy, for example, happens when people speak and act on their own behalf and take a more active role in their own community (Williams and Shoultz, 1982). The emergence of self-advocacy groups such as People First has been a significant development in recent decades.

People First encourages people with learning difficulties to take control of their own lives. It began in North America and was started in the United Kingdom in the mid-1980s. The organisation has local groups and a national office that supports the development of self-advocacy. Many self-advocacy groups are associated with it. The groups are made up of people with learning difficulties and are often based in training centres, hostels and special schools. The growth of these groups has been influenced by the ideas surrounding normalisation and social role valorisation mentioned previously (Brandon, 1995).

There are now a number of other national umbrella organisations for user groups and self-help groups. The British Council of Organisations of Disabled People is one example of this. User organisations played an important part in bringing about the direct payments legislation and the anti-discrimination legislation (Priestley, 1999). Carers UK is an umbrella organisation for carers' groups and was an active lobbyist for the Carers (Recognition and Services) Act 1995.

Developments in the self-organisation of users of welfare services illustrate much diversity amongst user groups (Barnes, 1997). The self-help organisations enable previously unconsulted groups to have their voices heard and make their views known. Barnes argues that these organisations are not solely concerned with the redistribution of material goods or with changing the balance of power, 'they are also seeking to change the nature of the discourse within which notions of age, disability and mental disorder are constructed' (ibid., p. 70). Literature on user empowerment and self-help for older people is less in evidence, although there have been some initiatives to give older people a voice in community care (Thornton and Tozer, 1995; Jack, 1995; Cormie, 1999; Carter and Beresford, 2000).

Links can be made to the material in the previous chapter. There was material in Chapter 6 on the importance of social networks and the concept of social capital was introduced. Clearly, self-help groups and user-organisations are a means to helping people develop social networks and expand their social capital. Community development has also been a means of doing this and we turn to this next.

Community development and community care

Community care takes place within a community context and a useful avenue to explore in this respect is the connection between user involvement and community development. Historically, many users have been segregated from the general population and socially excluded from mainstream society. User empowerment needs to be considered not only in terms of individual empowerment but also from the perspective of collective empowerment, empowerment to relate to the wider community and empowerment as part of the wider community (Barr *et al.*, 1997).

Identifying opportunities for empowerment was made difficult by the individualistic interpretation of community care during the 1990s. Earlier chapters have noted the process whereby a person is assessed against 'eligibility criteria'. Individuals who meet these criteria receive a service. The structures were set up to target individuals in 'greatest need'. In the Department of Health's guidance for practitioners on the community care changes (DoH, 1991b), there was no mention of a community approach. The emphasis was on setting up individual care management with individual assessment, care plans and packages of care. Thus, discussions of empowerment frequently just related to 'individual' empowerment and did not consider the other collective aspects. The possibilities provided by such individual 'empowerment' were inevitably narrow and limited.

Techniques and skills of community development play a part in the process of empowerment. The philosophy of community development focuses on people who are excluded or oppressed, the structural causes of exclusion or oppression, collective social change, high levels of participation and the process of change. The strategies and skills employed in community development have been drawn on a great deal in health promotion work and there are advocates for them in other areas of health work (Clarke, 1998). Sometimes the language or 'capacity building' is used as a way of describing the outcomes of this sort of work.

So much community care is provided within the community by family, friends and neighbours that it is not sensible to ignore the contribution of community work practice and skills to the total picture. I have argued elsewhere and in more detail that 'there needs to be a strategy that links community care into the strengths and weaknesses of the local community, the support networks and the lack of support networks, the churches, the community groups, the friendship patterns' (Sharkey, 2000a). There are possibilities of linking community development and community care through the user-empowerment rhetoric of the community care changes that in turn can be linked to the participatory traditions of community work.

We have seen that the development and growth of self-help groups, user groups and new social movements was one of the most interesting and inspiring aspects of the 1980s and the 1990s. This bottom-up growth raises the question of whether community care practitioners can link up with such groups in a way that is constructive and neither patronising nor colonising (that is, the practitioners should not take over). Are there ways in which practitioners can move away from their individualistic orientation towards greater user involvement and a more collective approach? The rhetoric of empowerment and user involvement used by agencies and the Department of Health can be drawn on to develop approaches that are more collective and participatory in nature. It continues to be the case that service-user involvement and participation is extolled in much government guidance.

Barr *et al.* (1997) list the values that community care and community development have in common: empowerment, social inclusion, partnership, needs-led approaches, and participation. They outline four ways in which community development overlaps with user involvement and thus has a role to play in community care:

- *Collective user influence on service provision.* This concerns the level of control and influence users and carers have over the services they use. The emphasis here is on self-advocacy and empowerment. Suggested examples range from community advisory committees to full user control of the service.

- *Collective policy planning influence.* This concerns the influence users and carers have over the policy framework that determines the services they receive. Examples here are the care forums that have been introduced by a number of authorities.
- *Community service provision.* This is service provision by users/carers on their own or by other community organisations.
- *Supportive communities.* The focus here is on changes and developments within neighbourhoods to create more favourable conditions for community care users or carers to become integrated into community life. Examples include good neighbour schemes, volunteering, circles of support and community education.

It is through the user-empowerment aspects of the community care changes that a link can be made to collective empowerment of care users and carers as communities of interest and to the role neighbourhoods can play in supporting community care. There is clearly a gap between rhetoric and reality in respect to user empowerment and community development can help to bridge this gap. Barr *et al.* (ibid., p. 141) present a number of case studies and argue that 'The case studies illustrate that community development is an approach which takes forward user involvement and participation and seeks to make clear links between care user groups and the society of which they are a part'. They urge that a stronger connection be made between community care and community development, saying that health and welfare professionals have embraced the language of concepts such as empowerment, participation and anti-discriminatory practice but have continued to pursue an individualistic approach to assessment and care planning. 'This myopia constrains the application of these concepts which find their real potential in collective action by and with communities to meet their own needs and pursue more relevant and effective services' (ibid., p. 150).

In a later study called *Caring Communities*, Barr *et al.* (2001) make a further contribution to the debate on how community development approaches to community care can promote participative, inclusive and supportive communities. This was a three-year action-research project on the impact of a community development approach to community care. There was a focus on four sites in Scotland and all four provided evidence of the benefits that community development approaches can offer in the context of community care.

If community care is to be truly empowering, it must empower people beyond their role as services users and carers. The aim is that previously marginalised and excluded people should become part of the local community and participate in it (Barnes, 1997). Barnes argues that the concept of community care needs to be widened to include community participation. If this is to be achieved 'It has to involve enabling people to participate in decision making processes about services, and in social, economic and political life more broadly' (ibid., p. 172).

A wider interpretation of community care is needed rather than a narrowing down to individual care packages. With this wider vision, it is possible to draw on the real strengths of users/carers to ensure that they make an effective contribution to the well-being of society. Community work approaches give ideas on how this wider vision can be achieved by practitioners. Practitioners of preventive healthcare have been at the front of the field in recognising the importance of community work in achieving a positive change in health at the local level (DoH, 1999b).

Models of empowerment

So far this chapter has considered government policy in relation to empowerment and then the influence on practice of the idea of independent living, the social model, normalisation, and the user movement. The practice of community development has also exerted some influence and could be taken further.

Most people claim to be in favour of empowerment, but is it simply the case that it is a contested term and different people apply different meanings to it? One way of exploring this is to think in terms of models of empowerment. One such model is that of the consumer who has a greater choice of services. This is called the consumerist model. An alternative model is where the user has greater control over the services and this can be called the democratic model (Beresford and Croft, 1993; Robson *et al.*, 1997; Carter and Beresford, 2000).

The consumerist model views users as consumers. Governments of the 1980s and the early 1990s aimed to impose market ideas on public service provision, and consumerism in the public services meant bringing market principles to bear. A key element of the consumerist approach to public services is that the user has more choice because of the greater range of services on offer. The purchaser/provider split is seen as central to this. The user has more and clearer information on the services available and who the services are for. Representation and advocacy may be available for users. There is access to a complaints procedure. In this model these are all key factors in making the services more responsive to users as consumers.

While the consumerist model has been associated with New Right politics and ideas, the democratic model has been associated with the emergence of disabled people's organisations, self-advocacy and service users' organisations and movements (Croft and Beresford, 1999). Central to the democratic model is the idea of users having a greater say in and control over services as well as greater choice. This model draws on traditions of community work and community action, which have always strongly emphasised power and participation issues. The consumerist model emphasises information for users and user involvement but is not really concerned with user power. Customers in a shop can choose between the selection of products on display and have a certain choice between different shops, but they do not determine what is put on the shelf, that is, they have very little power over the selection of products from which to choose.

'Choice' became an increasingly used work in relation to health and social care provision during the early years of the new century. Governments wanted to increase choice for patients and service users. It could usually be seen within the consumerist model and the points about consumerism in a general sense made in the previous paragraph can be applied to consumerism within the health and welfare services. Choice is limited. For example, an older person may be able to choose between three day centres, but that is as far as it goes. The democratic model would raise issues about users having a say in whether they want day centres, where the day centres should be located, what goes on in them and how decisions are taken within them. The consumerist model lacks this dimension of power over what is provided and how it is provided.

So far, two models of empowerment have been described. In reality it may be more helpful to think in terms of a 'ladder of empowerment' with a succession of steps or stages. In their training pack on community care and community development, Barr *et al.* (1997, p. 21) describe the stages shown in Box 7.4.

Box 7.4 A ladder of empowerment

'Manipulation – Creating an illusion of participation resulting in disempowerment.
Informing – Telling people what is planned.
Consultation – Offering options and listening to feedback.
Deciding Together – Encouraging others to provide additional ideas and join in deciding the best way forward.
Acting Together – Deciding together and forming partnerships to act.

Supporting Independent Community Interests – Helping others to do what they want.'

If you are a practitioner then try to apply the above ladder to a situation or situations with which you are involved.

Some of the ideas discussed earlier in the chapter can be applied to the ladder in Box 7.4. It was noted earlier that disability groups campaigned for many years for direct payments to be made to them so that they could pay for their own care. This sprang from the independent living movement for people with physical disabilities. Schemes such as this are close to 'supporting independent community interests'. As you move to the other end of the ladder, users have less and less control over the services on offer and less and less say in how they are provided.

Social exclusion and regeneration

Chapter 1 introduced the notion of social exclusion in relation to community care. It also stressed the need for practitioners to make connections between personal problems and the wider structural issues such as poverty or inadequate housing. This section returns to that theme by looking at social exclusion and regeneration. Socially excluded people have often been geographically concentrated in certain areas and so area-based regeneration policies have often been a key part of the policy response.

Tackling social exclusion has been a major theme of New Labour policies before and since the 1997 election and social exclusion is now part of the common currency of debates about social policy in the United Kingdom. The Social Exclusion Unit (SEU), was set up in 1997 and was based in the Cabinet Office and reported directly to the Prime Minister on how to 'develop integrated and sustainable approaches to the worst housing estates, including crime, drugs, unemployment, community breakdown, and bad schools, etc.' (SEU, 1998). The SEU's remit is confined to England, although similar policies have been adopted in the rest of the United Kingdom.

In the book *Understanding Social Exclusion*, Hills argues that one of the advantages of looking at social exclusion is that it gives attention to aspects of deprivation which go beyond cash and material living standards (Hills, 2002, p. 242). The concept can include the dynamics of why some groups (such as older people or people with mental health problems) may be marginalised. Resolving this requires the development of closer links between community care developments and social exclusion policies (Sharkey, 2000b). This view is echoed in a report by the Social Exclusion Unit in 2004 which said, 'Community care policies need to be broadened to embrace more effectively the social exclusion agenda. While the extent of change in this policy area has been extensive over the past decade, there is a case for widening the scope of this work and extending the ambitions of care in the community' (SEU, 2004b, p. 8). In 2004, this same report for the Social Exclusion Unit examined the impact of government policy on social exclusion among older people. It included an outline of the gains made by the reforms in community care, notably in helping to maintain very dependent older people in their own homes for longer periods. However, it noted the limitations of the impact of community care policies on the social exclusion of older people. It summarised these as:

- 'limitations of low-level preventive work with older people;
- continuing problems in maximising user-involvement and empowerment;
- problem of continuing focus on survival needs to the detriment of inclusion of older people into mainstream activities;
- limited integration of community care with community development;
- continuing difficulties faced by marginalized groups such as those with mental health needs, black and minority ethnic elders, and carers.' (2004b, p. 65)

The report examined the possibility of refocusing the community care debate around social inclusion issues and argues in the conclusion that 'promoting social inclusion is an integral part of community care practice' (ibid., p. 89). A later report from the social exclusion unit (SEU, 2006) stressed the 'multiple exclusion' of many older people. It advocated a Sure Start service for older people and cross-government action to tackle social exclusion in this age group.

Similarly in 2003 the Social Exclusion Unit were asked to consider what was needed to reduce social exclusion among adults with mental health problems. The ensuing report (SEU, 2004a) focused on what more could be done to assist people with mental health problems to enter and retain work and have the same opportunities for social participation and access to services as the general population.

Within the overall policies on social exclusion there has been an emphasis on neighbourhood renewal or neighbourhood regeneration. In poor areas (or areas particularly identified as in need of regeneration), there are often a large number of community care concerns. This might be because there are high concentrations of people with mental health problems or drug/alcohol problems. Problems that affect whole communities are not best responded to by individualistic responses by health and social care services. During the

1980s and the early 1990s, the emphasis of regeneration was on economic objectives and the role of the private sector. Regeneration policies and approaches since the mid-1990s, however, have clearly included a social dimension (SEU, 1998). These government policies have an important role to play in developing a sensible way forward in community care. Community care workers can help by moving on from 'picking up the pieces' in a poor area to helping the whole community and its people to move forward, improve the quality of their lives and have some say over the future of their area.

An individualistic approach is a highly inadequate response by itself and other approaches are required. As Davey (1999, p. 37) has written, 'People who are seriously disadvantaged in society rarely have single problems – they have multiple interlocking problems. . . . Empowerment must address all their problems together if it is to be meaningful.' A broad approach, tackling the interlocking problems and looking for the common causes, is essential.

A problem that many of those involved in regeneration projects have stressed is that the mainstream public services in poor neighbourhoods are frequently ineffective (SEU, 1998, p 10). In spite of numerous demands for programmes to be 'bent' towards the needs of poor areas, there is little evidence that this happens (ibid., p. 38). The requirement here is for health and social care agencies to bend their provision towards poor areas and use their resources in an imaginative way. There is a need to analyse the problems, understand what the government is trying to do with area-based projects and work with the policies rather than against them. A key point is that the mainstream welfare services and indeed societal structures can encourage and create exclusion or inclusion. As Parkinson (1998, p. 34) states, 'Explicit urban strategies can make a difference, but mainstream programmes make a greater one'. Thus mainstream policies and practices within health and social work need to change.

The need for the involvement of local people and for community development to be a central part of the regeneration strategy is frequently stressed. For example, 'The most powerful resource in turning around neighbourhoods should be the community itself. Community involvement can take many forms: formal volunteering; helping a neighbour; taking part in a community organisation. It can have the triple benefit of getting things done that need to be, fostering community links and building the skills, self-esteem and networks of those who give their time' (SEU, 1998, p. 68). It is important for workers in mainstream programmes such as community care to back the policies and practices of the local regeneration strategy. It is acknowledged that regeneration requires local participation to be successful, so it follows that community care activities must also be participatory and collective.

Mutual aid and self-help are seen as crucial to addressing the issues of poverty, exclusion and regeneration (Burns and Taylor, 1998). The Labour government has placed some emphasis on communitarian ideas and mutual aid. Community work strategies and skills have much to offer in relation to tackling social exclusion and community work has a history of both tackling social divisions and working to empower people (Mayo, 1998).

Regeneration strategies are frequently concerned with issues of direct interest to community care service users. A housing strategy needs to have supported housing as a central part of its agenda. An employment strategy needs to have policies to assist disabled people enter the job market. Hence the importance of community care users and workers being involved directly and closely in the development of local policy.

Practice issues

As an exercise, if you are a practitioner, reflect on a situation in which you are involved - this could be to do with an individual, a group or the wider community. Try to place that situation on the ladder of user involvement prescribed in Box 7.4. What are some of the blockages to moving to a position of greater user empowerment on the ladder? Can those blockages be removed?

Service users often need information in order to challenge decisions made about them. A range of ways in which decisions on care management can be challenged are given at the end of Chapter 4. Practitioners need to be knowledgeable about these mechanisms in order to provide information at appropriate times. Practitioners should also find out which user groups are operating in their area of work and consider the ways in which support might be given. Care should be taken to act sensitively and to avoid the 'I know best' attitude exhibited by some workers.

In this chapter it is argued that there was more rhetoric than reality about user empowerment in the community care changes. Other changes and influences have, however, encouraged empowerment in different ways and the influence of the independent living movement, the social model of disability, normalisation, the user movement, and community work has been discussed. All have provided some vision, progress and encouragement when other pressures have forced practice into an individualistic and bureaucratic mode. It has been further argued that policies on social exclusion and regeneration offer opportunities for practitioners to engage in the wider debates and practices (focusing on participation, involvement and change) that are evolving. To avoid this would be to miss the opportunity presented by the Department of Health:

> 'More widely, social services can make an important contribution to wider local authority-led programmes to tackle the problems of homelessness, poor housing conditions, and social exclusion in deprived neighbourhoods.' (DoH, 1998a, para. 6.23)

Ideas of anti-oppressive practice or anti-discriminatory practice are relevant to all sections of this book but perhaps especially in relation to this chapter. Thompson's (2006) PCS analysis provides a method for thinking about this. The P level stands for the personal level of thoughts, feelings, attitudes and actions. C stands for the cultural level of shared ways of seeing, thinking and doing. S relates to the structural level of society and the structures of power and oppression that exist in society (ibid., pp. 26–30). This provides a framework for relating individual and personal matters through to cultural issues and to the wider structural issues that we have referred to throughout the book.

There is a tendency to see empowerment in purely individual terms. While this is important, this chapter has stressed the desirability of collective empowerment strategies through involvement in self-help groups and community development. Practitioners need to consider how they can acquire skills that are relevant to this and be open to the possibilities it presents. Stewart (1993) argues for much more coverage in nursing education of working in partnership with self-help groups. Healthcare may too easily fall into the pattern of individual diagnosis and the prescription of drugs in cases where mutual support may be more relevant and helpful.

Priestley (1999) has looked at the Derbyshire Integrated Living Scheme in the context of the wider user movement and national and international policies and developments. Practitioners need to try to make the same connections between local work and wider national and international developments. A quotation from Priestley's book is worth reflecting on in this respect: 'There are many battles to be won and the sheer scale of those which remain requires the maintenance of a visionary agenda for the liberation of disabled people. As the example of disabled people's organisations in Derbyshire shows, acting locally and thinking globally has proved to be good maxim for action' (ibid., p. 226).

Further reading

Swain, J., French, S., Barnes, C. and Thomas, C. (2004) *Disabling Barriers – Enabling Environments* 2nd edn ((London: Sage). This textbook on disability studies has a variety of chapters examining particularly aspects of the social model of disability.

Thompson, N. (2006) *Anti-Discriminatory Practice*, 4th edn (London: Palgrave). Thompson, N. (2003) *Promoting Equality*, 2nd edn (London: Palgrave). Both books provides a framework for understanding discrimination, oppression and social divisions.

Journals that have debated in much more detail some of the issues relating to disability contained in this chapter are *Disability and Society*, the *British Journal of Learning Disabilities* and the *Journal of Applied Research in Intellectual Disabilities*.

World Wide Web sites

The British Council of Disabled People was set up in 1981 and is an umbrella organisation representing over 120 disabled people's groups. Its web site is at www.bcodp.org.uk

The website of the National Centre for Independent Living is designed to be a resource on independent living and direct payments for disabled people and others working in the field and can be found at http://www.ncil.org.uk