King's Fund

Trends in Rehabilitation Policy

A review of the literature

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- The need, within health care, for greater recognition of its importance and for improvements in availability was recently reflected in the continuing health care guidance requiring explicit eligibility criteria.
- It is increasingly recognised that rehabilitation, including social rehabilitation by social services authorities, offers opportunities for reducing unnecessary residential and nursing home placements.

The meaning of rehabilitation – origins and debate

The origins of rehabilitation lie in a number of separate developments since the First World War, and these roots are evident in the continuing debate about its aims and nature. Rehabilitation is a function of services and not necessarily a service in its own right.

There seems to be an emerging consensus that:

- The primary objective of rehabilitation involves restoration (to the maximum degree possible) either of function (physical or mental) or of role (within the family, social network or workforce).
- Rehabilitation will usually require a mixture of clinical, therapeutic and social interventions that also address issues relevant to a person's physical and social environment.
- Effective rehabilitation needs to be responsive to users' needs and wishes, purposeful, involve a number of agencies and disciplines and be available when required.

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An emphasis on restoration:

- Enables rehabilitation to be distinguished from primary prevention and maintenance.

Provision of and responsibility for rehabilitation

Provision is health dominated:

- Most rehabilitation services are provided by the health service in hospital settings. The potential of other settings (e.g. primary and community) is under-developed.
- Although rehabilitation is an explicit element in some social care services and implicit in others, social services authorities have not fully recognised the role they could potentially play.
- The rehabilitative goals of social care services (domiciliary, day and residential) need to be fully recognised and clarified to expand opportunities in the community.

Responsibility is not clearly defined:

- The respective *responsibilities* of health and social care authorities for rehabilitation are often disputed: a joint approach offers one way of resolving such disputes, as well as providing a more appropriate service for users.
- Both health and social care agencies have an interest in improved rehabilitation outcomes.

Trends in the availability of provision

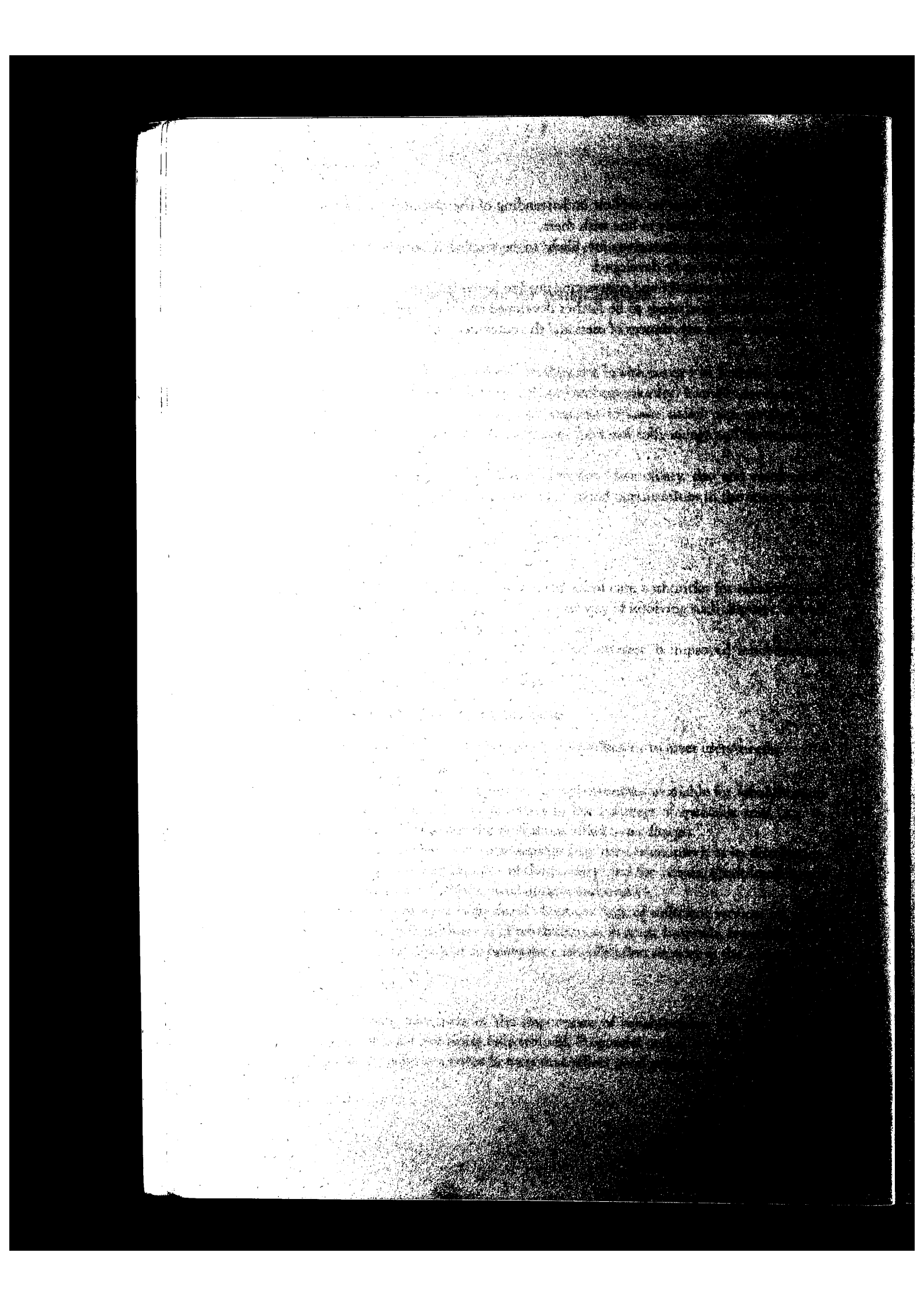
Rehabilitation services are often unavailable or insufficient to meet users' needs:

- There are indications of a decline in the opportunities available for rehabilitation over the past decade, despite increases in the numbers of specialist staff (e.g. in rehabilitation medicine and the professions allied to medicine).
- Deficiencies are evident – in some settings (e.g. the community); in its distribution – leading to gaps in certain parts of the country; and for certain conditions/disease states (e.g. back pain, arthritis, head injuries and stroke).
- Particular concerns have been raised about the lack of sufficient services for older people – with a marginalisation of rehabilitation in acute hospitals, fewer long-stay geriatric beds, and a lack of compensatory rehabilitation services in the community.

Conclusion

There is increasing awareness of the importance of rehabilitation but, in practice, opportunities for it are not being fully realised. Purposeful action is needed to develop rehabilitation, organising services in ways that reflect good practice. If progress is to be made:

- It is essential to have an explicit understanding of the objectives of rehabilitation and organise effectively in line with them.
- Changed financial incentives are likely to be needed if improved rehabilitative opportunities are to be developed.
- Rehabilitation practice and contracting need to be evidence-based.
- The evidence base needs to be further developed and improved, placing particular emphasis on the experiences of users and the outcomes.



Introduction

In the summer of 1996, the King's Fund and Audit Commission organised a workshop on the subject of rehabilitation. Through earlier work, the two agencies had become aware of increasing dissatisfaction about access to rehabilitation opportunities within the current health and social care systems. A report produced after the workshop set out the ideas and concerns of participants and included a number of suggestions for action for the development of further rehabilitation provision (Robinson and Batstone, 1996).

In order to inform the development process, the agencies commissioned two literature reviews: one to examine the effectiveness of existing rehabilitation services, the other to discuss definitions of rehabilitation, responsibilities for rehabilitation services within health and social care, and trends in the availability of provision. The Social Policy Research Unit at the University of York was commissioned to undertake the second of those reviews; their report is presented here.

The literature that could be drawn upon was limited. There is a considerable body of literature on rehabilitation practice and specific projects, but little on policy issues. Many of the issues mentioned at the workshop were based on anecdote and reflected concerns which have not yet been included in publications. Several fascinating questions were raised, such as the availability of rehabilitation in different specialties – but literature on such topics is sparse. Although rehabilitation is mentioned in various policy documents and commentaries, such references are sometimes made only in passing and little detail is available: moreover, comments are often based on assertion or belief rather than hard evidence. In other instances, the term 'rehabilitation' is not used, even though it could be appropriately applied: this is particularly likely in relation to social care.

Given the number of gaps in the more readily available literature, we have drawn on a range of sources including 'grey' literature (such as health authorities' strategic plans), and some of our sources have reflected opinion rather than objective evidence. We acknowledge that we have not examined the full range of publications available – especially among the less widely available material. Nevertheless, we believe that, within the timescale, we have taken account of the main issues and main policy developments.

Structure of this report

Chapter 1 considers the reasons why rehabilitation is fast becoming an important issue on the policy agenda. Chapter 2 explores the nature of rehabilitation: its history and definitions. Then we examine the types of rehabilitation currently available and the contexts in which it is provided. Chapter 4 looks at trends in provision and the accessibility of rehabilitation services, while Chapter 5 draws suggestions for the future development of services.

Chapter 1

Background

Key points

- A number of key reports and commentators have emphasised the importance of rehabilitation – and described deficiencies in its availability.
- In the NHS, there have been pressures to reduce length of stay in hospital but earlier discharges are only possible if patients are able to manage in their own homes or other supported accommodation. Rehabilitation has an important role in ensuring that discharge can take place once initial clinical interventions have been completed.
- The need, within health care, for greater recognition of its importance and for improvements in availability was recently reflected in the continuing health care guidance requiring explicit eligibility criteria.
- It is increasingly recognised that rehabilitation, including social rehabilitation by social services authorities, offers opportunities for reducing unnecessary residential and nursing home placements.

Developments within the health service

A number of concerns have come together during the 1990s to place rehabilitation on the policy agendas of both NHS and social care agencies.

In the NHS, there have been pressures to reduce lengths of stay in acute hospitals, increase the provision of day surgery, and place more diagnosis, treatment and monitoring services within the community (Henwood, 1995). Such developments have partly resulted from cost-containment strategies and a wish to ensure that expensive hospital resources are used in the most efficient way possible (Office of Science and Technology, 1995). Earlier discharges from hospital, however, are only possible if patients are able to manage in their own homes or other supported accommodation. Rehabilitation has a key role in ensuring that discharge can take place once initial clinical interventions have been completed (Health Committee, 1996; Henwood, 1994).

The profile of rehabilitation has also been raised through a number of recent reports. The White Paper on *The Health of the Nation* called for 'an appropriate balance' between prevention, treatment and rehabilitation (Secretary of State, 1992: para 1). The Clinical Standards Advisory Group (1994) subsequently reported on the importance of rehabilitation in relation to back pain; the Audit Commission's national report (1996a) on services for older people with hip fracture found that few hospitals had a satisfactory system for arranging rehabilitation.

Professional bodies, too, have stressed the importance of rehabilitation in improving quality of life and reducing costs (e.g. BGS and RCN evidence to the Health Committee,

1996), a call which was endorsed by the Health Committee (1996) and which reflected reports from international bodies (Council of Europe, 1988; WHO, 1981, 1994). Such documents have influenced some health care agencies as they have developed rehabilitation strategies and projects (e.g. Norfolk Health, 1996; Rockingham Forest NHS Trust, 1995). Additional reasons for focusing on rehabilitation have included demographic changes (increasing numbers of older people and the survival of more younger people with severe physical impairments), a growing emphasis on the need to enhance quality of life and independent living, and a focus on community-based health care (Office of Science and Technology, 1995; Symington, 1994; WHO, 1981).

The introduction of continuing care policies has provided a major stimulus to thinking about rehabilitation. The initial circular (DH, 1995) stressed the need for recovery and rehabilitation services, particularly for older people, and called for explicit protocols and eligibility criteria in relation to rehabilitation. Subsequent guidance (DH, 1996a) was critical of policies which set restrictive time limits for rehabilitation and also noted that rehabilitation should be part of longer-term care arrangements (including care in residential or nursing homes or in people's own homes), not just in the post-acute phase.

A later circular noted a growing awareness of the need to provide rehabilitation (DH, 1996b). However, an accompanying report, based on an examination of current policies, reported that some policies did not define eligibility criteria for rehabilitation and there was a lack of clarity in some published criteria (Henwood, 1996). Many policies did acknowledge, nevertheless, that further work was needed on the amount and type of rehabilitative services to be purchased. The subsequent announcement of additional resources for priority services in England, including continuing care, led to the funding of a number of rehabilitation services (DH, 1996c, 1997a).

One of the central aims of the continuing care guidance was to oblige health and local authorities to clarify their responsibilities for the provision of long-term care. Policies were initially intended to specify NHS responsibilities for continuing care (including rehabilitation), though it was expected that these would be drawn up with local authority agreement. In practice, some were jointly prepared, while others appeared to reflect health authorities' views alone (Henwood, 1996). Although many referred only to NHS responsibilities for rehabilitation, some indicated that other agencies also had a role to play (e.g. South Humber Health Authority, 1996); some policies specifically mentioned the rehabilitative role of social services and the independent sector in relation to social functioning (Lincolnshire Health, 1996).

Social services' role in rehabilitation

Social services authorities had an additional reason for becoming increasingly interested in rehabilitation. For many years, the term 'rehabilitation' in the social care context had tended to refer to vocational rehabilitation for disabled people, social rehabilitation for people with mental health problems, or social and daily-living skills learning for those moving out of long-stay psychiatric or (what were then known as) 'mental handicap' hospitals. Although the NHS and Community Care Act 1990 did

not make any specific reference to rehabilitation, some saw it as offering new opportunities and challenges for the development of rehabilitation within community care as a means of improving the lives of people in the community (Scottish Office, 1993). One of the purposes of the Act was to stem the rise in placements of older people in residential and nursing homes and to support people, instead, in the community. Nevertheless, the number of places in such homes continued to rise: from 470,400 places in 1991 (in the private, voluntary and local authority sectors) to 509,400 in 1995 (Laing and Buisson, 1992, 1996).

The high costs associated with such placements, together with the imperative to support people in the community, led some local authorities to develop rehabilitation facilities for older people (SSI, 1996a). Such facilities offer an opportunity to reduce unnecessary institutional placements, and existing units have demonstrated the potential for considerable cost savings (DH, 1996b; Health Committee, 1996). They also prevent the loss of independence associated with institutional care and therefore provide benefits to older people themselves (Health Committee, 1996). In addition, rehabilitation was increasingly seen as having a role to play within long-term care. The Association of Directors of Social Services suggested, for instance, that the public debate about long-term care had ignored the rehabilitative potential of such care 'in the promotion of dignity, self-worth and inclusion in citizenship' (evidence to Health Committee, 1996: para 49).

Chapter 2

What is rehabilitation?

Key points

- The origins of rehabilitation lie in a number of separate developments since the First World War, and those roots are evident in the continuing debate about its aims and nature.
- Rehabilitation is often a function of services, not necessarily a service in its own right.

There is an emerging consensus that:

- The primary objective of rehabilitation involves restoration (to the maximum degree possible) either of function (physical or mental) or role (within the family, social network or workforce).
- Rehabilitation will usually require a mixture of clinical, therapeutic and social interventions that also address issues relevant to a person's physical and social environment.
- Effective rehabilitation needs to be responsive to users' needs and wishes, purposeful, involve a number of agencies and disciplines and be available when required.

An emphasis on restoration:

- Enables rehabilitation to be distinguished from primary prevention and maintenance.

Historical developments

One of the earliest forms of rehabilitation took place in spa resorts, where people with rheumatological problems sought relief from their symptoms (Scottish Office, 1993). The beginnings of orthopaedic rehabilitation can be traced back to the First World War, when military orthopaedic hospitals were established to treat wounded personnel and help them return to active service (Mattingley, 1981). It was then that prosthetic services, physiotherapy and occupational therapy came into being (Clarke, 1987; Scottish Office, 1993). At around the same time, the high incidence of tuberculosis led to the development of rehabilitation which aimed to return people to employment (Mattingley, 1981).

In the 1940s, the Second World War again focused attention on the need to assist large numbers of casualties to return to military service (Clarke, 1987). Subsequently, the doctors who had worked in rehabilitation hospitals (particularly in the RAF) took their

skills and interests with them when they returned to civilian employment (Chamberlain, 1992). The rehabilitation needs of war victims, combined with the effects of the polio epidemic of the early 1950s, led to the development of rehabilitation departments: the emphasis was now on rehabilitation rather than convalescence as a means of recovery (Squires, 1996).

The subsequent Piercy Committee report of 1956 viewed rehabilitation as part of a curative process which enabled potentially economically active people to be re-incorporated into the social system (Alaszewski, 1979). This report included services for people with mental health problems or learning difficulties; however, it did not examine rehabilitation services for older people. Nevertheless, geriatric rehabilitation was also establishing itself as an important part of medical services. During the 1930s, Marjorie Warren enabled many older people to leave hospital and either return home or be admitted to residential care in the community. Since then, rehabilitation has been seen as an integral part of medical services for older people (Strasser, 1992).

Other developments have taken place more recently. First, the concept of rehabilitation has been applied within an increasing number of medical specialties, including neurology, respiratory disease, cardiology, ophthalmology and audiology, to the extent that it has been stated that any doctor with chronically ill patients should be interested in rehabilitation (Aitken, 1982; also Symington, 1994; WHO, 1981). Nevertheless, the need for rehabilitation often remains unrecognised (Association of British Neurologists *et al.*, 1992). Many doctors have preferred to focus on curative treatment, and rehabilitation services have frequently developed from individual clinicians' enthusiasm rather than through strategic planning (Beardshaw, 1988).

Secondly, there has been a shift towards a tripartite model involving institutional provision, outreach and community-based services (Bakheit *et al.*, 1996; Clarke, 1987; WHO, 1994). Although specialist centres still exist – including, for instance, rehabilitation units for older people, Young Disabled Units and Spinal Injury Units (Aitken, 1982; Kalra, 1996) – rehabilitation services are now available in other hospital settings and in the community.

The location and nature of rehabilitation services form part of – thirdly – a broader debate about the need for specialist provision. The Tunbridge Committee argued in 1972 for the creation of a new medical specialty based on physical medicine and rheumatology to be the focus of new rehabilitation departments at district general hospitals. This proposal was resisted by other specialties, notably orthopaedics, geriatrics and psychiatry, which would have had to rely on the new specialty for rehabilitation expertise and whose control over their own area of work – and associated resources – would consequently have been reduced (Alaszewski, 1979); moreover, the concept of a separate department challenged the convention of individual clinicians being responsible for patient care (Beardshaw, 1988). Professions allied to medicine were resistant to supervision by medical staff (*ibid.*).

A decision by the British Association for Rheumatology and Rehabilitation nonetheless cleared the way for the creation, in 1990, of rehabilitation medicine as a separate specialty (Chamberlain, 1992). Tension remains, however, between calls for specialist services to be available for patients (BSRM, 1993; Turner-Stokes and Frank, 1990), and the view that rehabilitation skills should be available as an integral part of mainstream clinical services (BGS, 1997; Strasser, 1992).

A fourth development concerns the content and aim of rehabilitation services. Here, two changes have occurred. Whereas many rehabilitation services for younger people were focused initially on vocational services, now they take account of a broader range of aspects of people's lives. Partly as a result, but also because of the growth of specialist employment services, this has led to less focus on vocational needs within health and social care services. There has also been a growing awareness that medical rehabilitation cannot be fully successful if it does not take account of the practical circumstances in which people live, and that they may need support with a wide variety of aspects of their lives other than purely medical ones: social and environmental issues have increasingly been recognised as important (McLellan, 1997; Warren, 1981; Williams, 1996). Moreover, rehabilitation may not only involve a combination of medical and social considerations. In some cases, social rehabilitation may be the sole or primary concern; for instance, where people are being resettled from long-stay hospitals into the community or people with mental health problems are being supported in the community.

Fifthly, the growing emphasis on user involvement in health and social care services has had an impact on rehabilitation. This emphasis originates, in part, in the growth of consumerism and an increasing interest in citizens' rights – as evidenced in the Citizen's Charter and Patient's Charter. It also reflects the growing voice of the disability movement. Zola, for example, called in 1982 for a change 'from doing something to someone, to planning and creating services with someone' (p.396). Other disabled people have highlighted the need to take account of disabled people's views and enable them to exercise choice and control over the way they lead their lives (Bracking, 1993; Oliver, 1993a).

Questions have been raised about the values that underpin rehabilitation services: for instance, blaming individuals for difficulties in achieving rehabilitation goals, rather than recognising that it is the social context in which they live that may cause the problems (Shakespeare and Watson, 1997). In some cases, disabled people may prefer less emphasis to be placed on physical independence, and more on the provision of appropriate equipment or personal assistance (French, 1993). There has been a call to change the relationship between disabled people and professionals. Instead of professionals taking control of or seeking to manage individuals' lives, disabled people have asked professionals to be a resource to them, share their expertise and knowledge, and support them as they seek to achieve their own goals (Finkelstein, 1991; French, 1994).

Participation, empowerment and independence now form part of the rehabilitation debate (Moore, 1995), and many practitioners acknowledge the need for service users to play an active part in the rehabilitation process (Craddock, 1996; Williams, 1994).

A genuine change in the relationship between professionals and users will not be easy, however, it will inevitably involve a change in the balance of power (Moore, 1995). Nevertheless, some commentators suggest that professionals are primarily enablers, and that the credit for achieving desired results must lie with disabled people themselves. One consultant has written that rehabilitation is something that disabled people achieve 'with (or in spite of) the help of other people' (McLellan, 1991a: p.13).

The concept of rehabilitation

The literature contains a range of ideas and definitions on rehabilitation: what it involves, who does it, and when it is carried out. We have taken account of this diversity in our outline for translating the concept into practice.

In common with others, we would argue that the core objective of rehabilitation is restoration, whether of function (Warren, 1981), capability (RCP, 1986), independence (Tallis, 1992), or physical and mental health (Mattingley, 1981). The specific focus may be on physical, psychological, social or environmental issues (NHS Executive, 1997; Scottish Office, 1993). Where the full restoration of function is not possible, the aim of rehabilitation will essentially be to restore function, and reduce the impact of illness or an impairment as far as is possible (Blais, 1994; McLellan, 1997; Young, 1996). Restoration also involves learning, whether of knowledge or of skills (Council of Europe, 1988; Gompertz and Ebrahim, 1992; McLellan, 1997); this can mean the relearning of previous skills or adapting them to new circumstances (Moore, 1995; NHS Executive, 1997).

The first concern, after the onset of an illness or impairment, is generally with the restoration of physical function. It is in this area that medical practitioners, nurses and therapists play a key role. Some definitions of rehabilitation indicate that acute care and the stabilisation of a person's condition need to be completed before rehabilitation can start (UN, 1993). Others advocate, for instance in the case of traumatic brain injury, that rehabilitation should begin 'at the roadside' (SSI, 1996b, leaflet: p.3) or 'with the initial emergency response' (Welsh Affairs Committee, 1995: p.16). The Department of Health's guide suggests that rehabilitation should be an integral component of acute care (NHS Executive, 1997). It is important, nevertheless, to make a clear distinction between acute care and stabilisation on the one hand, and rehabilitation on the other.

A concern with clinical interventions might suggest that this stage of rehabilitation is likely to be based on a 'medical model' of disability. This approach sees the locus of disability as lying within the individual and following directly from particular impairments (Basnett, 1995). A purely medical model of rehabilitation would emphasise the central role of clinical interventions aimed at restoring function and would expect the individual to take personal responsibility for achieving improvements. The physical location of rehabilitation within a clinical/medical setting is also likely to emphasise the authority of professional staff in deciding what kind of rehabilitation is required and how it should be carried out.

Proponents of a 'social model' of disability argue that disability is socially created and is a product of the institutions, organisations and processes that constitute society (Oliver, 1993b). In applying this to rehabilitation, advocates of the social model are critical of what they see as the 'medicalisation' of the rehabilitation process: they argue, instead, for an approach which acts to reduce environmental barriers to independent living and enables individuals to take control of the rehabilitation process (Silburn, 1993).

There is clearly a difficulty in applying a purely medical model of disability to rehabilitation. Disabled people may not require any medical or clinical help relating specifically to their impairment. People who need rehabilitation will usually require a mixture of clinical and social interventions. Young (1996) uses the term 'hard' rehabilitation for the hands-on treatment provided by medical staff and therapists: this corresponds to a concern with physical functioning. However, the same staff may also undertake 'soft' rehabilitation, which involves talking to, listening to and counselling patients. In addition, many rehabilitation practitioners actively seek to help service users define their own objectives, and visualise their role as helping them to achieve those objectives (McLellan, 1991).

A second difficulty with the purely medical model is that most rehabilitation practitioners do not see the objectives of their work in terms of restoring physical function. In practice, they often try to address all relevant issues within a person's physical and social environment (Chamberlain, 1992; McLellan, 1997; WHO, 1981). At one level, this involves the immediate environment within which a disabled person lives and might require the provision of appropriate equipment and adaptations, or possibly resettlement to a new home. Rehabilitation may also be concerned with the restoration of role – for instance, within a family, social network, or job. In this case, help may be required from a variety of agencies or individuals – including, for example, social workers, counsellors, employment agencies or disability organisations. McLellan (1997) suggests that many disabled people's difficulties could be more appropriately solved by political or cultural changes than by medical or therapeutic intervention – although such changes might fall outside the scope of rehabilitation.

Many practitioners appear to work with a mixture that includes both clinical and social dimensions. Rather than seek to attribute styles of working to one model rather than another, it is more helpful to acknowledge the various components of rehabilitation and the variety of issues that need to be addressed. In the following section, we consider an integrated approach for a service that will appropriately meet users' needs.

Achieving the objectives

The following seem to contribute to effective rehabilitation:

Responsiveness to users' needs and wishes

In the first place, effective rehabilitation requires the active participation of service users (Craddock, 1996; Williams, 1994; see also the review by Sinclair and Dickinson, 1998). Good practice does not simply mean asking them if they accept professionals' decisions.

It also means they must be able to decide what is done, by whom, when, and how.

Multi-disciplinary and inter-agency working

The need to address a wide range of aspects of a person's life means, secondly, that rehabilitation has to draw on the skills of a number of different specialties, professions and organisations. Multi-disciplinary teams offer one means of co-ordinating the contributions of different disciplines (Bakheit, 1995). Where such teams do not exist, it is particularly important to make sure that service users receive a full range of services, and to co-ordinate staff with different skills and ensure they work together towards the same ends. The Scottish Office (1993) suggests that co-ordination might be enhanced through the appointment of rehabilitation co-ordinators, based in local authorities, who would bridge the gap between health and employment services. The importance of local and health authority co-ordination has also been emphasised in reports on specific needs (for instance, in relation to traumatic brain injury – SSI, 1996b) or policy issues (such as continuing care). The Government's response to the Health Select Committee's report on continuing care noted that the consideration of rehabilitation should be integral to the assessment of anyone with continuing care needs, and should be included in their care package (DH, 1996d).

Available when required

Thirdly, good practice indicates that rehabilitation should not be restricted to pre-determined time limits (Young, 1996). Some people may require more time than might usually be provided; others may need help on repeated occasions. Rehabilitation should be available on a needs basis, not as a form of crisis management (Baker *et al.*, 1997).

Clear rehabilitative purpose and goals

If rehabilitation is to have a distinct objective and identifiable features, it is necessary to distinguish it from other processes. A key feature is that it must be purposeful. Some services may not include restoration or rehabilitation as specific objectives but may nonetheless still achieve them. In such circumstances, it may be useful to highlight their rehabilitative components and increase awareness of their functions. Where the primary focus is on a different objective, as in the case of convalescence, it would be confusing to include it within the same definition.

Rehabilitation can sometimes play a preventive role. After a person has experienced an illness or injury, rehabilitation serves a restorative function and can also help prevent further deterioration or the recurrence of such incidents. Lewin *et al.* (1992) developed a self-help rehabilitation programme for people with acute myocardial infarction, which was aimed at preventing further cardiac problems. For older people, some rehabilitation programmes are designed to prevent falls and associated injuries for those who have already experienced such difficulties (Moffett, personal communication). In these examples, however, the focus is on secondary prevention after an illness or injury has taken place; such prevention is part of the rehabilitative process. This needs to be distinguished from primary prevention which seeks to prevent an illness or injury

occurring in the first place. Primary prevention does not have a restorative component and is not a form of rehabilitation.

Maintenance, similarly, does not involve restoration. Where the impacts of impairments are long-term, the aim of service interventions may be to help people maintain a particular level of functioning or lifestyle. In this case, there is no restorative element and services do not have rehabilitation as an underlying objective. Where rehabilitation takes place, however, any degree of restoration needs to be maintained (Moore, 1995; NHS Executive, 1997; Turner-Stokes and Frank, 1990). In this context, maintenance does form part of the overall rehabilitation process, although it might more appropriately be considered a form of secondary prevention.

In some cases, the aims of rehabilitation will overlap with those of other services. This may be the case with, for example, goals such as the maximisation of potential (Chamberlain, 1992; Gompertz and Ebrahim, 1992) or of a person's independence and autonomy (Beardshaw, 1988), improvements in quality of life (Young, 1996; Williams, 1994), or an increase in life satisfaction (Blais, 1994). While not denying their importance, such objectives do not represent features that clearly distinguish rehabilitation from other services.

The same is true of services that have been termed 'habilitation' as a means of drawing out their similarities with rehabilitation (Moore, 1995). Habilitation, however, does not include the objective of restoration, and it is more accurate to refer to it as development, not a form of rehabilitation.

A function of services

Although it is important not to confuse rehabilitation with other objectives, this does not mean that rehabilitation is the sole prerogative of rehabilitation services that are explicitly named as such. Rehabilitation is a function of services which have a rehabilitative component, whether explicit or implicit: while it may be carried out by specific, specialist rehabilitation staff, it can also be undertaken by staff who have broader remits. Where rehabilitation is an implicit activity, it is important to acknowledge that it is taking place. Only then will it be possible to focus attention on the potential benefits of rehabilitation, define objectives, and ensure the continued provision of rehabilitation services.

Conclusion

In the final section of this review, we will consider the implications of these factors for rehabilitation policy and practice. First, however, we need to take account of the contexts in which rehabilitation is currently available.

Chapter 3

Who provides rehabilitation?

Key points

- Most rehabilitation services are provided by the health service in hospital settings. The potential of other settings (e.g. primary and community) is under-developed.
- Although rehabilitation is an explicit element in some social care services and implicit in others, social services authorities have not fully recognised the role they could potentially play.
- The rehabilitative goals of specific social care services (domiciliary, day and residential) need to be fully recognised and clarified to expand opportunities in the community.
- The respective *responsibilities* of health and social care authorities for rehabilitation are often disputed: a joint approach offers one way of resolving such disputes, as well as providing a more appropriate service for users.
- Both health and social care agencies have an interest in improved rehabilitation outcomes.

Medical services

Rehabilitation is seen as an integral part of the work of geriatricians, neurologists and other specialists dealing with both acute and long-term medical conditions. However, it is not always specified in service contracts. In such circumstances, there is a danger that it will not be provided – to the detriment of patients and potential loss of rehabilitation facilities and expertise (Young *et al.*, 1997). In the case of geriatric services, a move in the 1980s to integrate acute and rehabilitative services was followed by pressure for high throughput and a focus on acute services – with the result that specialist rehabilitation components have arguably been demoted and partially lost (*ibid.*; Ebrahim, 1994).

Young *et al.* (1997) have suggested that rehabilitation represents a high-volume core service, but with low 'marketable' potential. Although additional funding, such as the Department of Health's initiative on priority services (NHS Executive, 1996a; Secretary of State for Health, 1996), allows some resources to be directed towards rehabilitation, this does not ensure that it will be better integrated within mainstream services.

Although the numbers of patients seen in mainstream services are high, it is not possible to say how many of them receive rehabilitation. Specialist rehabilitation units are relatively few in number and often based in academic units with a particular interest in the subject. Although most rehabilitation services are still hospital-based, some hospital departments have developed outreach services (Bakheit *et al.*, 1996).

Professions allied to medicine

Remedial therapists (including physiotherapists, occupational and speech therapists) play a key role in rehabilitation in both hospital and community settings. A primary aim of physiotherapists is to enhance mobility and physical independence (Chartered Society of Physiotherapy, 1992). Occupational therapy, for its part, involves 'the treatment of physical and psychiatric conditions through specific activities in order to help people reach their maximum level of function and independence in all aspects of daily life' (College of Occupational Therapists, 1984: p.1). Both groups of therapists may work alongside other specialties, either in multi-disciplinary teams (Normand *et al.*, undated) or – in the case of occupational therapists – as employees of social services authorities (SSI, 1993). In a listening exercise on primary care conducted by the NHS Executive (1996b), some therapists stated, however, that neither GPs nor the NHS really understood the range of skills they had to offer or how effective their input could be.

GPs and primary health care

Differing views have been voiced about the role of GPs and primary health care teams in rehabilitation. McLellan (1997), writing as a rehabilitation specialist, argued that rehabilitation is not included in GP training and that GPs are not equipped to carry out this task. Gompertz and Ebrahim (1992), themselves specialists in the care of older people, suggest that GPs may not recognise the need for early rehabilitation. On the other hand, Smith and Forbes (1996) believe that primary health care teams do have an important role in rehabilitating older people. In the case of GP fundholders, the Scottish Office (1993) suggested they could provide rehabilitation themselves or, alternatively, incorporate rehabilitation services into contracts with other providers – as is already happening (Drinkwater, 1996).

The Audit Commission (1996b) reported that more fundholders than non-fundholders now offered physiotherapy and speech therapy at their practices. Nevertheless, both the NHS Executive's (1996b) listening exercise on primary care and the subsequent White Paper (Secretary of State for Health, 1996) noted a need for closer working between primary health care staff and therapists: the fact that this appeal has been made reflects the lack of understanding that many primary health care staff have of the benefits that rehabilitation can bring, and a resulting failure to meet users' needs (Drinkwater, 1996). This lack of understanding would appear to be reflected in the very few references in the literature to rehabilitation in the context of primary health care.

Nursing

Nurses have always played an important role in specialist rehabilitation units (Sheppard, 1994) or as specialists themselves, for instance in relation to stoma care, continence or rheumatology (Gale and Gaylard, 1996). Elsewhere, there has been an increasing recognition of the need to define the nursing role in rehabilitation, particularly in multi-disciplinary teams for older people (Ford, 1991). In addition, Williams (1994) has stressed the importance of rehabilitation in nursing care for older people, as a means of

either restoring them to a 'normal life' or enabling them to achieve greater independence in aspects of daily living.

Day hospitals

One setting in which the role of rehabilitation is in dispute is the day hospital. Rehabilitation is only one of the functions of day hospitals – others being maintenance, assessment, and medical, nursing and social care (Brocklehurst and Tucker, 1980; Murphy and Rai, 1984). Some have argued that the amount of rehabilitation provided in day hospitals is too small (Gompertz and Ebrahim, 1992). Others feel that, although day hospitals provide an opportunity for individual therapy and group rehabilitation activities, they are an artificial setting for rehabilitation, which should preferably take place where people live (Gloag, 1985). Even in the early 1980s, calls were being made for rehabilitation to be included within in-patient care, domiciliary and day care services, which would be more cost-effective than day hospitals (Tucker *et al.*, 1984). Such calls have been repeated recently, with the suggestion that resources would be better deployed in out-patient and day wards, improved primary health care and community-based rehabilitation; alternatively, day hospitals could be given a different role as resource centres for older people (Lubel and Denham, 1993).

Other NHS provision

Not all schemes which carry out a rehabilitative function choose to identify themselves as such. Although part of health authority provision, an integrated living team in North Derbyshire was critical of the medical setting in which it was located; it specifically described itself as not being involved in rehabilitation, which it associated with a medical model of care (Silburn, 1993). Its primary aim, nonetheless, was to support disabled people in the community and its functions coincided with the broad range of issues included above as being part of the rehabilitation process.

In social services

Within social care, the term 'rehabilitation' tends to be mentioned only in a few specific contexts. Many community care plans do not refer to it at all. One exception is the Doncaster community care plan (1996–2001), which notes the need for rehabilitation for people with mental health problems and for an integrated rehabilitation service for people with physical impairments. Although references to rehabilitation in other contexts are infrequent, it could be argued that rehabilitation is an implicit objective in other social care settings, and that a recognition of the rehabilitative value of some social care services might help to clarify the potential benefits of a more focused and explicit approach.

Support for people with mental health problems

Although the term 'rehabilitation' is often used in relation to both social work support and multi-disciplinary projects for people with mental health problems, it is generally indistinguishable from other social work and social support services (Hugman, 1989;

Pilling, 1991). The tasks of one community psychiatric rehabilitation team (funded jointly by health and social services) include: increasing social contact and reducing isolation, practical help with self-care skills, and increasing independence (Tough, 1995).

Social work with other service users

Although social work is concerned with maintenance and support to enable people to lead preferred lifestyles, it can also aid independence and encourage the learning or relearning of skills for daily living. Social workers may be members of multi-disciplinary teams, either in hospitals or in the community, and can contribute to the rehabilitation objectives of those teams. Nevertheless, financial constraints and organisational changes introduced with the new community care arrangements in 1993 have led to the relocation of many hospital-based social workers to other settings (Manthorpe, 1996). In some places, social workers play no part in hospital discharge arrangements (Worth, 1994); where their role has changed to that of care managers, their focus is typically on assessing social care needs and arranging domiciliary support or residential or nursing home placements. Rehabilitation is not generally seen as part of social work and social workers' potential input into rehabilitation may remain untapped. The SSI's report (1996b) on services for people with traumatic brain injury noted that the role of social workers is crucial in enabling people to return to the community and in work with their families. The Health Advisory Service (1997b) similarly highlighted the need for social services authorities to be aware of the potential rehabilitation needs of older people.

Occupational and other community-based therapy services for people with physical or sensory impairments

One area of rehabilitation in which social services authorities have traditionally played a key role has been in the provision of occupational therapy and other services for people with physical or sensory impairments (Conyers, 1992; SSI, 1996b). These services have usually been provided by occupational therapists or other specialist staff in service users' own homes. In some cases, occupational therapy and equipment services have been jointly provided with health agencies – this being considered a particularly effective way of delivering services to users (NHS Executive, 1996b).

Domiciliary care

Some writers have discussed rehabilitation in the context of home care services (e.g. Gompertz and Ebrahim, 1992). The Department of Health's (1996b) evaluation of continuing care suggested that intensive home care schemes could offer an alternative to specialist rehabilitation provision. However, we have not been able to find any literature describing such usage. In the case of mainstream home care services, it is likely that assessments of need are carried out without specific consideration being given to rehabilitation needs.

Day care

Social services day centres have a number of roles, including the provision of care, companionship, personal support and social recreation (Brearley and Mandelstam,

1992; Scottish Office, 1993). By bringing people together and providing services, day centres may play a rehabilitative role – though this is not always explicit. Indeed, the precise aims of day centres are often unclear, and this has led to confusion about the emphasis to be placed on treatment, occupational activities and rehabilitation (Horobin, 1987). The same is true of other units which include day care provision, as in the case of 'elderly people's integrated care systems' or older people's resource centres (Higham, 1991; Hollingbery, undated). The literature itself appears to have little to say about the role of day centres in relation to rehabilitation policy. However, work in progress by the Social Services Inspectorate and King's Fund suggests that the rehabilitative role of day centres could be expanded to develop independent living skills, facilitate social engagement and promote social integration (Robinson, 1997). This study notes, though, that there is a danger of centres adopting a more active rehabilitative role and their atmosphere changing to that of 'clinics'.

Residential care

The provision of rehabilitation has not traditionally been seen as a function of residential care either. However, the Department of Health's review of continuing care policies highlighted the role of social services authorities in providing rehabilitation for people in nursing and residential homes, which would enable at least some of them to return to their own homes in the community (DH, 1996b).

Since the introduction of the new community care arrangements in 1993, some social services authorities have also begun to develop short-term residential provision for older people, with the aim of preventing admissions to permanent residential care (Rickford, 1997; SSI, 1996a). Some of these services specifically mention rehabilitation as a core objective; in other instances the term 'rehabilitation' is not mentioned at all, even though the service is essentially the same (ALM Medical Services, undated; Younger-Ross *et al.*, 1995).

Short-term breaks

As in the case of day care, there is a lack of clarity about the precise objectives of respite care, or short-term breaks, and rehabilitation is seldom specified as one of their aims (Nocon and Qureshi, 1996). However, some services are intended to enable users to develop independent living skills and to enhance their quality of life (Flynn *et al.*, 1994): such aims are effectively the same as those of social rehabilitation. Some policy statements also suggest that respite care or 'short-term breaks' offer an opportunity to provide rehabilitation, though this is seen as an adjunct to the breaks rather than one of their integral functions (DH, 1995).

Inter-agency working

For many people, especially those with complex problems, rehabilitation will involve a range of professionals, potentially from several agencies, and their work will need to be co-ordinated. This would be the case, for example, with the provision of an accessible home, access to the immediate environment or appropriate transport (McLellan, 1992).

At a strategic level, too, rehabilitation requires inter-agency collaboration (NHS Executive, 1997; Scottish Office, 1993). Some health authorities' rehabilitation plans acknowledge the role of social services and the voluntary sector in developmental work (e.g. Norfolk Health, 1996). Henwood (1994) suggests, in relation to hospital discharge, that investment in rehabilitation offers real benefits for both health and social care agencies, and is therefore an appropriate issue for joint commissioning. Although joint ventures such as equipment stores or occupational therapy services have been in place in some areas for many years, such examples remain uncommon. Lewis and Wistow (1996) argue, in common with other writers on joint planning, that the division of responsibilities between agencies makes joint strategies difficult to achieve, and that this is particularly the case where the benefits of investment by one agency will be felt by another. This means, for example, that if the main benefit of investment by social services is the prevention of admissions to hospital, there would be no immediate incentive for them to participate. The British Society of Rehabilitation Medicine has suggested, on the other hand, that if health services pay for rehabilitation, the benefit of reduced care needs would in fact accrue to social services (BSRM, 1996).

It would appear, nevertheless, that some social services and health authorities have found ways of collaborating to their mutual benefit and that of service users. Hospital-at-home schemes, for instance, offer an opportunity to bridge the gap between health and social care and to provide support for older people who can be discharged from hospital provided they receive additional short-term rehabilitation at home (Lewis and Castleton, 1992). Community rehabilitation for people with mental health problems may also involve an inter-agency approach (Tough, 1995).

Responsibility for providing rehabilitation

Despite examples of agencies providing rehabilitation services either on their own or with other agencies, disputes and concerns about responsibilities still arise.

Within the NHS, the specific remit of individual agencies can lead to their unwillingness to take responsibility for an overall programme of rehabilitation (McLellan, 1991a). Moreover, acute services may not see rehabilitation as part of their role: instead of incorporating it into their service, they may view it as a separate activity to be carried out either by other staff or after acute treatment has been completed (Young *et al.*, 1997).

A further area of dispute concerns the responsibilities of health and social care agencies for the provision of rehabilitation. The SSI (1996b) report on traumatic brain injury recommended that local authorities should work alongside health authority commissioners to meet social care needs within rehabilitation services. The Health Select Committee (1996) suggested that local authorities themselves should set up social rehabilitation schemes and purchase more short-term rehabilitation services. Nevertheless, some local authorities see the provision of rehabilitation as an NHS responsibility. One Director of Social Services is reported as stating, in relation to continuing care, that 'rehabilitation for someone with a broken leg is not social services' responsibility' (Eaton, 1997: p.12).

The Association of Directors of Social Services has also questioned the extent to which local authorities should be funding home care, where this represents a form of rehabilitation that is arguably the responsibility of the NHS (Rickford, 1997). Prior to being elected to government, the Labour Party (1997) argued that problems over bed-blocking, re-admissions to hospital and inappropriate placements in residential or nursing home care, could arise because of a lack of appropriate 'recuperation' services. It suggested setting up a pilot project, modelled on a transitional care scheme being planned by hospital and community trusts in Oxford. It saw this project, and any subsequent extension of the idea, as being the responsibility of the NHS.

Some of these inter-agency problems reflect the shifting boundaries – and cost-shunting – that have taken place between the NHS and local authorities in the past few years (JRF, 1996). If users' needs are to be appropriately met, however, rehabilitation should be a comprehensive and integrated service which bridges gaps between different agencies (Baker *et al.*, 1997). This will require a recognition that both health and social care agencies have an interest in improved rehabilitation outcomes. Funding will be needed to ensure that these services are provided, either by individual agencies or jointly. At a practice level, staff need to be aware of service users' potential needs for rehabilitation. They also need to recognise that the skills of other professional staff, including in those other agencies, can help to achieve rehabilitation goals.

Chapter 4

Trends in the availability of provision

Key points

- There are indications of a decline in the opportunities available for rehabilitation over the past decade, despite increases in the numbers of specialist staff (e.g. in rehabilitation medicine and the professions allied to medicine).
- Deficiencies are evident – in some settings (e.g. the community); in its distribution – leading to gaps in certain parts of the country; and for certain conditions/disease states, e.g. back pain, arthritis, head injuries and stroke.
- Particular concerns have been raised about the lack of sufficient services for older people – with a reduction of rehabilitation in acute hospitals, fewer long-stay geriatric beds, and a lack of compensatory rehabilitation services in the community.

An improving situation?

Mulley wrote in 1994 of the success of geriatric rehabilitation during the previous 50 years. This was evident, he suggested, in the lower number of blocked beds, shorter periods of hospital stay, less unnecessary institutional care, reduced burdens on carers, and fewer crisis 'social' admissions (1994b). He did not, however, quote any specific evidence. A decade earlier, Mattingley (1981) noted that physiotherapy and rehabilitation departments now existed in many district general hospitals, and pointed to the rehabilitative work carried out by GPs and consultants. However, both he and Warren (1981) suggested there was a lack of comprehensive rehabilitation in the UK, a lack of progress in the previous 40 years and, indeed, a decline in medical interest in the subject in the 1970s. Warren believed that, even in those areas with relatively good services, many patients would benefit from more help.

Statistics on staff indicate an increase in the numbers of both rehabilitation specialists and professional staff allied to medicine. Since rehabilitation medicine became a separate specialty in 1990, the number of specialist rehabilitation medicine staff in England increased from 17.5 whole-time equivalents in that year to 94 in 1994 (DH, 1992, 1996e). During the ten years up to 1994, the number of (whole-time equivalent) physiotherapists employed in the NHS increased from 8,540 to 10,570 (a 24 per cent increase) and occupational therapists from 3,610 to 6,410 (a 78 per cent increase) (quoted by the NHS Executive, 1996b). Local authority occupational therapists increased from 893 whole-time equivalents in 1984 to 1,560 in 1995 (Barker, 1996; DH, 1993). Despite such increases, however, shortages of therapy staff have been reported (Beardshaw, 1988; Latto and Stevenson, 1985; NHS Executive, 1996b). In some cases, staff are deployed on non-rehabilitative work, for instance to carry out assessments. More staff would appear to be needed for rehabilitation than are currently available.

Variability and insufficiency

The literature suggests considerable variability in both availability and quality of rehabilitation, in different parts of the country and between specialties – but comments tend to be in general terms rather than on the basis of specific evidence (cf. Rickford, 1997). A survey of RCP members found that 72 per cent had 'problems' with rehabilitation (RCP, 1995), while the Association of Directors of Social Services suggested that rehabilitation was particularly lacking where health providers had divested themselves of non-acute beds (quoted by Rickford, 1997). The Scottish Office's (1993) working group on rehabilitation commented on the irregular distribution of services in Scotland, while nevertheless being 'impressed by the amount of good rehabilitation being performed by many specialties' (p.77).

Some comments refer to problems for people with particular needs. Wolfe *et al.* (1993) argued that the overall level of rehabilitation for people with strokes was low, especially for people not admitted to hospital. Variations and geographical inequity for stroke patients were also reported by Beech (1996). The *General Practitioner* magazine (1995) stated that, according to the available evidence, domiciliary therapy for post-stroke patients was often not available.

In the case of people with arthritis, NHS services are said to be 'practically non-existent' and individuals may have to arrange rehabilitation privately – at considerable cost to themselves and their families (Arthritis Care, personal communication). For people with back pain, waiting-lists for rehabilitation are said to be often very long, resulting in detrimental effects on people's ability to work and their overall quality of life (Moffett, personal communication). Rehabilitation services for people with neurological conditions, too, are said to be sparse and unco-ordinated (Association of British Neurologists *et al.*, 1992; Beardshaw, 1988).

A lack of specialist services for people with head injuries means that young patients are often inappropriately placed on psychiatric or psychogeriatric wards (Halle, 1992). An SSI report (1996b) found that, where people with head injuries have been placed on orthopaedic wards, rehabilitation was seldom provided. Therapists have stated that access to therapy services is inequitable (NHS Executive, 1996b), and Turner-Stokes and Frank (1990) suggested that remedial therapy is typically reduced or withdrawn when people return home from hospital – at a time when they probably need it most. A survey of registered blind people found that only 43 per cent had received rehabilitative training, and most of the 43 per cent expressed a wish for further assistance (Shore, 1985).

Although some writers state that geriatric rehabilitation services are better developed than in other specialties (Scottish Office, 1993), others suggest that specialist rehabilitation medicine concentrates on younger people, particularly those with more severe impairments (McLellan, 1994). Concerns have been expressed about services for older people. One survey of orthopaedic registrars at hospitals which admitted older people with hip fractures found that only 17 per cent had access to geriatric rehabilitation assessments (Pearse and Woolf, 1992). The Health Advisory Service (1997b) reported

that little rehabilitation was available to older people on non-geriatric wards. The Audit Commission's report (1996a) on care for older people with hip fractures described how, in one hospital, people were transferred to a rehabilitation ward only if there was a shortage of beds on the wards in which they were currently placed.

Age Concern's evidence to the Health Select Committee (1995) reflected concerns about the limited amount of physiotherapy, speech therapy and occupational therapy available for older people. In residential and nursing homes, particularly in the independent sector, rehabilitation is often not made available as part of the basic care package (Nazarko, 1995; Smith and Forbes, 1996): therapy services tend to be seen as additional to basic care and any resultant costs are passed on to residents or their relatives (Drinkwater, 1996). It is unclear whether the situation will be made worse by the BMA's statement that medical responsibility for patients in nursing homes should not be included among the core services covered by GPs' contracts (Glendinning and Lloyd, 1997).

Several reports refer to overt ageism in service provision (Health Advisory Service, 1997b; Titley, 1997). An audit of cardiac rehabilitation services in England and Wales found that 36 per cent of centres for people with acute cardiac conditions discriminated against older people (Thompson and Bowman, 1995). Older people with visual impairments have been found to be offered less rehabilitative training than younger people, despite having comparable needs (Latto and Stevenson, 1985; Shore, 1985). Although some health purchasers have stated that services should be non-ageist (e.g. Norfolk Health, 1996), professional attitudes may still reflect a *laissez-faire* attitude towards older people rather than a dynamic approach to rehabilitation (Gloag, 1985). Such an attitude is reinforced by suggestions that some older people themselves feel that rehabilitation is a waste of time and that resources should be spent elsewhere (Gompertz and Ebrahim, 1992) – suggestions that are certainly not shared by all older people (Titley, 1997).

It is difficult to establish whether older people are receiving more or less rehabilitation than before. Within geriatric services, the integration of acute and rehabilitative services, together with pressure for shorter hospital stays, would suggest that opportunities for rehabilitation are fewer than previously (Ebrahim, 1994). Some people feel that the open-ended availability of public funding for residential and nursing home placements in the 1980s and early 1990s led to a focus on cost-shifting and quick throughput rather than rehabilitation (Audit Commission, 1996c; BGS, quoted by Rickford, 1997; Young *et al.*, 1997).

It has been suggested that the introduction of the internal market in the NHS in the early 1990s led to pressure to save money: as a result, day hospital provision for older people was cut back, with scant regard to the needs it was seeking to meet (Dickinson, personal communication). The reduction of rehabilitation in acute hospitals, fewer long-stay geriatric beds, and lack of sufficient compensatory rehabilitation services in the community (Young *et al.*, 1997), would suggest that less rehabilitation is now available for older people. The implications of this are that the needs of older people

may not be fully addressed and their potential for independent living and maximum quality of life not realised. Inappropriate placements in residential or nursing homes can occur precisely because of the lack of opportunities for rehabilitation and recovery or a failure to consider the potential benefits to be gained from rehabilitation (DH, 1996b; Health Advisory Service, 1997b).

Differences in the availability of rehabilitation have also been identified among acute specialties. McLellan (1991a) and Halle (1992) note that, while there are more head injury patients than people with spinal cord injuries, there are more spinal injury units than head injury units in the UK. One NHS trust has stated that, within the 16–65 age group, there were particular shortages of services for people with degenerative neuromuscular conditions, strokes and head injuries (Rockingham Forest NHS Trust, 1995). Where specialist vocational rehabilitation is available for people with acquired brain injury, this can increase their chances of returning to open employment; however, this service is not available throughout the country (Health Advisory Service, 1997a). Moreover, the available provision is usually funded by charities or the European Union rather than the NHS or local authorities (*ibid.*). Some people receive compensation settlements (as awards from courts or insurance companies) and are then able to purchase rehabilitation services from the private sector (SSI, 1997b); however, other people with equal needs will be unable to obtain them.

We have not found much literature on rehabilitation services for black and minority ethnic communities. The Social Services Inspectorate (1997b) did find, however, that people from these communities were very much under-represented among the users of rehabilitation services for people with traumatic brain injury. Further research is needed to establish whether such inequity applies in other rehabilitation services.

Service users' views

Many service users feel that services such as physiotherapy are discontinued too soon and believe that, the longer they continue, the more they will improve (Lewinter and Mikkelsen, 1995). A survey of people discharged from hospital similarly found that 43 per cent felt they had not been fully rehabilitated (Victor and Vetter, 1989). Although the question of when to stop rehabilitation is often a difficult one (Rudd, 1996), this does not negate the dissatisfaction felt by disabled people and their carers about services (Baker *et al.*, 1997). It is also the case that patients are often not sufficiently involved in decisions about rehabilitation (Audit Commission, 1996a).

Lack of service integration

Some of the difficulties experienced by users are related to the poor integration and poor understanding of the role of rehabilitation within health care services (Audit Commission, 1996a; BSRM, 1993). Misunderstandings and rivalries between professional groups are said to lead to breakdowns in communication, both among professionals and with users and carers (Anon, 1988). Young *et al.* (1997) have commented, similarly, on the lack of good joint working between elderly care physicians and orthopaedic surgeons in relation to older people with hip fractures.

Vocational rehabilitation

In the past, a number of social services authorities have provided vocational rehabilitation services for disabled people, generally in the form of sheltered employment (Horobin, 1987; Martin, 1996; Scottish Office, 1993). More recently, some authorities have been involved in establishing employment initiatives for people with physical impairments, mental health problems or learning difficulties. Such projects have sometimes been joint ventures with other agencies and have attracted funding from a variety of sources, such as the European Social Fund, single regeneration budget, a contract with an Employment Service Placing, Assessment and Counselling Team, and the Mental Illness Specific Grant (as in the case of WorkLink, in Kirklees – though this project is now managed by the corporate services division of the local authority, and no longer the social services department). The WorkAble project in Bradford, which primarily assists people with physical impairments or learning difficulties to find employment in the open market, was a broader local authority initiative in the first place, with no specific social services input. Such examples would suggest that employment objectives are gradually being removed from the core objectives of social services authorities.

Problems and possibilities

Financial pressures have allegedly led to difficulties in rehabilitation services. A specialist rehabilitation unit noted a drop of one third in extra-contractual referrals in 1992, following the introduction of the internal market into the NHS (*Therapy Weekly*, 1992). The volume of contracts for surgical appliances has also reduced (Nazarko, 1995).

It would also appear that rehabilitation receives lower priority than other NHS services: emergency treatment or reductions in waiting-lists typically receive higher priority than rehabilitation, health promotion and other non-acute care (Lewis and Wistow, 1996; Young *et al.*, 1997). Such trends reflect public perceptions of priorities, as well as the views of GPs and hospital consultants (Bakheit, 1995). These trends are also said to be exacerbated by policy developments such as the Patient's Charter and hospital league tables, which focus on particular aspects of services (such as reducing waiting-times for elective surgery) to the exclusion of others (Nazarko, 1995). A greater focus on rehabilitation may well reduce the capacity to meet waiting-list targets (Wistow, 1995). When resource constraints indicate a need for cuts in services, it may be rehabilitation which suffers. In one case, a trust established a new service for people with acute back pain, but this subsequently had to be discontinued because of a lack of resources (Moffett, personal communication). In addition, the very existence of some community-based schemes, such as hospital at home projects, can put pressure on existing therapy services, which may then become unavailable to other potential users (Nazarko, 1995).

Within social services authorities, a number of developments have reduced the scope for rehabilitative work. Vocational services are often seen as the responsibility of other departments; domiciliary services are for people with complex support needs for whom rehabilitation may be less appropriate; the focus may be primarily on maintenance or

the prevention of deterioration; and domiciliary care packages are often limited to the cost of residential care.

However, a number of other factors have raised the profile of rehabilitation, including *The Health of the Nation*, the Clinical Standards Advisory Group report (1994) on back pain, the Audit Commission report (1996a) on hip fractures, calls from professional bodies and international agencies, and, most recently, the emphasis on rehabilitation within continuing care policies. Some health commissioners have highlighted the importance of rehabilitation within acute and intermediate services and in primary care development (e.g. Norfolk Health, 1996).

Providers themselves may be keen to offer rehabilitation in order to obtain a competitive edge over other providers and to meet a need for specific rehabilitation services. Some projects have been established to discover hospital patients with rehabilitation and continuing healthcare needs and ease access to appropriate care (Kalra, 1996). In some places, social services authorities have established rehabilitation projects, particularly for older people. Elsewhere, such projects have been implemented under the continuing care challenge fund initiative. Their impact will need to be evaluated to determine whether they meet rehabilitation needs more effectively than before.

Chapter 5

Future directions

Key points

- There is increasing awareness of the importance of rehabilitation but, in practice, opportunities for it are not being fully realised.

Purposeful action is needed to develop rehabilitation, organising services in ways that reflect good practice. If progress is to be made:

- It is essential to have an explicit understanding of the objectives of rehabilitation and organise effectively in line with them.
- Changed financial incentives are likely to be needed if improved rehabilitative opportunities are to be developed.
- Rehabilitation practice and contracting need to be evidence-based.
- The evidence base needs to be further developed and improved, placing particular emphasis on the experiences of users and the outcomes.

The value of rehabilitation

The importance of rehabilitation is increasingly being recognised. More medical specialties include it as part of their service and it covers a wider range of aspects than simply physical functioning. In the health and social care sectors (at both a local and national level), rehabilitation is seen as a means of easing discharge from hospital, reducing inappropriate long-term placements in institutional care, improving the quality of service users' lives, and offering a more cost-effective use of resources. Disabled people, too, are calling for better rehabilitation facilities in order to help them lead independent lives.

Evidence, however, suggests that opportunities for rehabilitation are not currently being realised. A number of new schemes are available. In many places, though, rehabilitation services are unavailable or insufficient, and there are marked disparities between different geographical areas and users with different needs. Services for older people, in particular, are often poor: this is despite the good practice of many individual staff and the existence of some innovative projects.

Achieving better services

There are many ways in which services can be organised. The literature contains various suggestions concerning the relative merits of specialist and generalist services, as well as calls for more therapists, more hospital beds or more provision within the community. It is not our aim to suggest an ideal service configuration. However, we believe it is essential to be clear about the underlying objectives of rehabilitation and the values that underpin good practice.

Clarity of purpose

If the benefits of rehabilitation are to be fully recognised and maximised, it is necessary to draw a clear distinction between rehabilitation and other service functions. We have suggested that the primary aim of rehabilitation is restoration. Other goals may be included, but it is the focus on restoration which distinguishes rehabilitation from other services.

Responsiveness to users' needs and wishes

The literature indicates that service users should play an active part in their rehabilitation. At present, however, there often appears to be a lack of communication or negotiation with them; some service users may not even be aware that rehabilitation is taking place; and sufficient systems to ensure full partnership with them are not in place. In addition, the success of rehabilitation is often perceived solely in terms of physical functioning, not in relation to other aspects of their lives that they may be concerned about. If genuine partnership is to take place, services must be responsive to users' needs and wishes – rather than users having to accept (or reject) the views and judgements of professional staff.

Inter-agency working

A holistic view of rehabilitation calls for an acceptance that health and social care agencies have a shared interest in effective rehabilitation. Some rehabilitation teams already co-ordinate the inputs of staff with different skills and from different agencies. Elsewhere, it is important that health care providers recognise the need for other inputs. Social services authorities, too, need to acknowledge their role in rehabilitation and not see this purely as a health care responsibility. Not only would this be a more appropriate way of meeting the totality of users' needs, it would also contribute to local authorities' own objectives (for instance, in enhancing users' quality of life or preventing unnecessary admissions to residential homes). Not least, collaboration would help to reverse the trend of shunting responsibilities across agency boundaries.

For joint working to be effective, however, it is necessary for agencies to share a set of common values and have a common understanding of the concept and objectives of rehabilitation. Political and/or financial incentives are also likely to be needed if improved rehabilitation opportunities are to be developed.

Evidence-based practice and contracting

Sinclair and Dickinson's review (1998) shows that a good deal of information is available about the effectiveness of rehabilitation, though gaps still remain. Such information needs to underpin rehabilitation practice and the commissioning of services which will achieve desired objectives.

Rehabilitation should be explicitly incorporated into service contracts. The contracting process must recognise that rehabilitation can be a function of a variety of services, and need not be limited to specific specialist settings. It must also take account of the

principles of good practice that have been identified in this review. Both commissioners and providers should be able to specify, for instance:

- in which service contexts rehabilitation is carried out
- the scope and goals of rehabilitation packages for individuals
- the amount of say that users have in defining what rehabilitation takes place, who provides it, when and how
- whether rehabilitation is available when needed, rather than on the basis of pre-determined time limits
- the extent of multi-disciplinary and inter-agency working in rehabilitation packages
- the extent to which desired outcomes are achieved
- whether outcomes are achieved in the most cost-effective way.

Development and research issues

Where there are gaps in knowledge about the effectiveness of rehabilitation, or different views about appropriate ways of meeting needs, pilot projects offer a means of filling them. If the usefulness or shortcomings of new developments are to inform future practice, however, it is essential that such projects should be fully evaluated. The way evaluation is carried out would itself need to be carefully considered. Rehabilitation generally involves individually negotiated outcomes and packages of services. In such circumstances, it may not be possible to carry out randomised trials which would require matched control groups and the attribution of outcomes to clearly identified inputs. A more qualitative approach may be indicated, which would take account of individuals' particular needs and both service and informal inputs.

One gap in current knowledge concerns the views of service users about rehabilitation and the types of services required. Research might usefully be carried out to seek disabled people's views about: the role of rehabilitation in independent living arrangements; the extent to which rehabilitation should be purely a medical issue and focus on aspects of physical function or whether it should encompass broader areas of people's lives; the amount of control that users should be able to exercise in deciding the kind of rehabilitation to be provided; and whether restoration should indeed be seen as the core objective of rehabilitation (or whether the emphasis should be on facilitating independent living according to the disabled person's own wishes). Further issues might include: the role that local authorities should play; how the need for rehabilitation should be assessed; and what criteria users would suggest for monitoring the effectiveness of rehabilitation services.

Conclusion

The provision of better services needs to be based on an understanding of the value of rehabilitation, an appreciation of the objectives of rehabilitation and the contexts in which it takes place, as well as information about users' views, clarity of purpose and process, and evidence about service effectiveness. The lack of sufficient opportunities for rehabilitation within current provision indicates a need for greater priority to be given to rehabilitation services in both local and national policy. Existing good practice

should be used to inform the development of alternative approaches to rehabilitation which meet users' needs more appropriately. Only then will it be possible to establish a range of services that offers equity for people with different needs, of different ages and in different localities.

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Over the last decade, rehabilitation in health and social services has been declining as the NHS and local government have focused on demands for acute and long-term care. Calls to reverse this decline have been made by patient groups and by agencies and professionals working in the health and social care arena.

Against this background, the King's Fund and the Audit Commission joined forces to carry out a major review of rehabilitation policy and practice. This report examines policy trends. It discusses the changing concept of rehabilitation, changing patterns of responsibility for provision and trends in the availability of rehabilitation. Recommendations are made for the future development of services.

Associated reading

Rehabilitation – a Development Challenge by Janice Robinson and Gifford Batstone

Effective Practice in Rehabilitation by Alan Sinclair and Edward Dickinson

Investing in Rehabilitation by Janice Robinson and Stuart Turnock

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