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REPORT
16

Reshaping Mental Health Services

Implications for Britain of US experience

Judy Turner-Crowson

King's Fund Institute

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present form. But responsibility for conclusions reached and for any errors or misinterpretations is mine alone.

Clearly, my own involvement in many of the issues discussed here has made it difficult to be impartial. I only hope that the explicit and implicit convictions, values and biases expressed do not obscure the main message: that all who care about the future of mental health services are in this enterprise together. We need to listen to each other and learn from each other to find the best way forward.

The author

Judith Turner-Crowson has been involved in mental health policy since the mid-1970s. From 1974 to 1983, at the US National Institute of Mental Health, she was responsible for designing and later managing the Community Support Programme described in this report, co-authoring the conceptual documents that underpinned the initiative. In 1984-85, she collaborated with the Mental Health Division of the World Health Organisation on an international study of mutual aid/self-help organisations for people with mental illness and their families. Since settling in Britain in 1989, she has been writing, speaking and consulting on mental health issues, and currently serves as policy officer for the Richmond Fellowship in London. This publication was prepared for the King's Fund Institute where the author was a Visiting Fellow in Mental Health Policy.

Foreword

Judy Turner-Crowson's message is that the UK is travelling down a similar path to the US – though a few years later – in shifting mental illness services from mental hospitals to the community. As in the US, the shift stems from a combination of influences, including humanitarian concerns about the negative effects of long-term hospitalisation. At the same time, the financial attraction of slimming down or closing hospitals is also a powerful driver for hard-pressed NHS managers.

But what are we going to put in the place of the mental hospitals? What ought to be the continuing role of secure units and sanctuaries? What community-based services must be in place if community care is not to be a hollow mockery? And what more can be done to avoid many of the problems that became so pervasive in parts of the US?

As Judy Turner-Crowson says, there are beacons of light in terms of good practice, but few convincing examples of a complete local service. Her contention is that to put comprehensive and appropriate services in place nationwide calls for a strong, systematic, shared process of local and national dialogue and joint action similar to that which was stimulated in the US by the National Institute of Mental Health's Community Support Programme. Since she was deeply involved in the programme from 1974 to 1983 she cannot claim to be objective about it, but she does offer a first hand account of how the programme worked and numerous ideas about possible adaptions of its principles to the UK. I am grateful to her for the way that she has put her experience at our disposal in the UK.

Whether or not the UK chooses to travel down the route she advocates, there is no doubt that we have a very long way to go before we will have in place a pattern of mental health services that any of us can view with confidence, let alone pride. We would therefore be foolish to ignore the chance to learn from what the Americans can tell us, though how we apply the lessons must be shaped by our own values and our own choices.

Robert J Maxwell
Secretary / Chief Executive
The King's Fund

Summary

Mental health policy in the United States and Britain has been moving in a similar direction for several decades, from 'institution' to 'community'-based services. The context, structures and policy approaches are different, but the problems are very similar. In both countries, there is a pressing need to speed the pace of service development in the community – especially for people most vulnerable to neglect. And in both countries awareness is growing that service provision must become much more responsive to what users, carers and minorities consider most important.

Part 1 of this report describes common concerns of the US and Britain in making a transition in mental health systems, noting that service deficiencies and policy problems identified by the US Congress and others in the mid 1970s bear a striking resemblance to those emerging since the mid 1980s in Britain.

Part 2 describes a 15 year effort by the US National Institute of Mental Health (NIMH) to improve community-based services nationwide, the *Community Support Programme* (CSP). This was designed to encourage the development in every district of flexible networks of services and supports for people with long-term and disabling mental health problems. The participatory planning process, the vision and concept of an adequate local system, the elements of a national strategy, and the outcomes and limits of the programme are examined within the broader US context, highlighting issues important for Britain.

Part 3 examines the situation in Britain in the 1990s. It then draws on US experience to examine six critical issues that must be effectively and continuously addressed at all levels to ensure better futures for people with mental health problems.

1 How clear and comprehensive are the *vision, philosophy* and *goals* concerning what needs to happen?
2 How satisfactory are the current ways of *involving stakeholders*, especially service users, carers and professionals, in shaping and refining goals, concepts and strategies?
3 What can be done to encourage a *systems approach* in every district? Is there a need for a unifying concept to integrate planning and action at local levels?
4 What can be done to clarify and strengthen national, regional and local *leadership* for continuous, planned, principled change?
5 How can *funding policies* and *incentives* be improved to support service goals?
6 What structures and processes are needed at each level to encourage *learning from experience* to improve policy and practice?

As the two countries struggle in different ways to shift to a new style of service, both face many forces of disintegration. These can be countered through an ongoing development process at national, regional and local levels. There is particular need for a well structured framework that brings stakeholders together at each level and across levels and sectors in order to clarify what is happening now, to create a shared vision of what needs to happen and to mobilise concerted action at all levels and across boundaries to 'make it happen'.

Introduction

This report examines national policy initiatives designed to encourage planned, principled change in opportunities and services for people considered to be mentally ill. By drawing on relevant aspects of US experience it is hoped to stimulate thoughtful dialogue in Britain about what needs to happen, how to 'make it happen', and dangers to avoid.

Of course, positive change in a field as complex and sensitive as mental health cannot actually be made to happen. But conditions can be created in which it is more likely. It can be facilitated. And to some extent it can be orchestrated. These developmental concerns require creativity and sustained effort at each level.

In a best-selling book called *Making it Happen: Reflections on Leadership* (1988), Sir John Harvey-Jones has argued that effectiveness in any complex enterprise depends in large part on enlisting people up and down the line in a clearly understood and widely shared sense of purpose. In mental health services, however, that is far from easy. Even the most fundamental ideas in mental health are controversial. There is debate, for example, about the nature and causes of various mental illnesses; some question the usefulness of the concept itself. Strong differences in ideology and approach among various mental health leaders compound the challenge of directing public resources and facilities toward socially valued purposes. This causes great difficulty in clarifying fundamental questions such as: 'What do you mean by mental health?', 'What is supposed to be happening?', 'Who is responsible for making it happen?' and 'How can we tell whether it is happening or not?'.

Further complexity springs from the fact that 'the mental health field has impaled itself on the border between health and social care' (Dorrell, 1992). Mental health leaders are generally unwilling to come down clearly on either side of the health / social care divide. But managing the interface is difficult, especially when this involves different sectors and levels of government. Problems may be compounded if the sectors are controlled by different political parties.

Other boundaries of the mental health enterprise are also difficult to draw. Clearly, judicial, employment, housing and income support policies outside the direct control of mental health policy makers are highly relevant to the nation's mental health, as are many other aspects of lifestyle, culture and social and economic policy. It has been observed, for example, that hospital admissions for schizophrenia increase during economic slumps, while recovery and rehabilitation rates increase in times of fuller employment (Warner, 1985). Given better work opportunities, fewer people would become disabled by mental illness, and people with mental illness or distress would have better prospects for recovery.

People working with those who are homeless have observed, not surprisingly, that being without a home causes severe distress, sometimes contributing to mental health problems (Joint Forum on Mental Health and Homelessness, 1991). On the other hand, social support networks among family, friends and neighbours are known to help reduce the negative consequences of stress; such relationships can help to prevent certain forms of mental illness and can contribute to a better outcome if it does occur (Newton, 1988). It is therefore increasingly recognised that mental health planners need to think beyond care and treatment alone; they also need to facilitate access by mentally vulnerable people to better housing, work opportunities and social support. But it remains difficult to draw the boundaries of mental health planning and provision.

In addition, some of what is done in the name of mental health is perceived by recipients and / or their families as extremely unhelpful and sometimes downright harmful (Chamberlin, 1988; Lawson, 1991). Yet it is equally true that many have benefited from modern treatments – even from controversial ones (Taylor and Taylor, 1989). This compounds the difficulty in defining 'needs' for mental health care. In many cases, mental health services most needed may not be those most in demand. Such complexities, combined with ambivalent attitudes toward the social control functions of mental health agencies, have often led to muddled mental health and related policies – in Britain, the United States and elsewhere.

At present, many would argue that there is clarity in British mental health policy about how long-term mental health services will *not* be provided in future. They will no longer be provided primarily in large mental hospitals. What is much less clear, however, is how such services *will* be provided and paid for, especially for people whose problems are serious and persistent. Too often, the new services are ill-defined, under-developed, unco-ordinated, poorly funded and vulnerable, with the danger that community care becomes a form of community neglect.

It is widely agreed that there is an urgent need to speed up the process of community service development in Britain. The NHS and Community Care Act 1990 offers a new framework for developing mental health and support services, bringing with it possibilities for both positive and negative change. In the new 'mixed economy of care', with a diversity of public, voluntary and private provision, creating a coherent services network in each district and locality will not be easy, especially with so much competition for scarce resources and so many different ideas about what is most important. Sustained and effective co-operation will be needed among a wide range of interest groups working across boundaries toward shared goals. Even under the best of circumstances this is difficult to achieve. But what can be done to create such conditions?

Experience from Britain's European partners, the US and other countries can shed some light on how to tackle such challenges. In the current British policy context, however, recent American experience is particularly relevant. Although US mental health policy is often viewed in Britain as an object lesson in what should be *avoided*, and with considerable justification, a wide range of public, voluntary and private providers has long been commonplace in the United States, and there are many other parallels with British experience.

No attempt is made here to provide a comprehensive comparative analysis of US and British mental health policy. Instead, the focus is on the *process* for encouraging planned, principled systems change. The dynamics of a particular US initiative are elaborated, drawing on the author's personal involvement at a national level. The aim is to stimulate constructive debate about the way forward within Britain and to encourage a more focused exchange of ideas and increased collaboration between the US and UK in the important areas of community support and rehabilitation in mental health.

Systems in transition: US and British mental health services

1

A revolution that treats people badly in order to do them good is a contradiction. The purpose of any revolution is that the people should benefit – not only ultimately, but even while the revolution is going on (de Bono, 1991, p.54).

In recent decades, both Britain and the US have been struggling in different ways with a similar challenge in mental health policy: how to shift from a focus on large mental hospitals to a diverse, decentralised approach, more in keeping with current philosophy, legal and judicial requirements and modern treatment technologies. In both countries, government rhetoric and policy documents have long emphasised 'community-based' services. Stated policy intentions are to develop a range of alternative facilities and services, involving many agencies, professionals, self-help and voluntary groups, to substitute for the old Victorian mental hospitals. But ensuring the intended benefits to people while a massive system change is underway remains a formidable challenge – in both countries.

The decline in mental hospital care

A common theme over the past few decades has been the declining role in long-term care of large public mental institutions. In the US, the public mental hospital census reached its peak of 559,000 in 1955. By 1975, the census had plummeted to 193,000, with a further reduction by 1990 to 92,059 (Centre for Mental Health Services, 1990). US psychiatric beds per 100,000 civilian population in state and county mental hospitals have declined dramatically – from 207.4 in 1970 to 40.4 in 1990 (Witkin *et al.*, 1990), although use of private and general hospital beds increased during the same period.

Because public mental hospitals are a state responsibility in the US, there has never been a national policy concerning mental hospital closures, and there is great variation from one state to another in use of such hospitals. Nonetheless, between 1980 and 1989, 34 public psychiatric hospitals closed, with 214 remaining open (American Hospital Association, 1990).

The US 'deinstitutionalisation' process has been described as having two distinct phases: a 'benign' phase from about 1956 to 1965, as public mental hospitals 'opened the back doors' for early release of new admissions and resettlement of higher functioning long-stay patients; and a 'radical' phase from about 1966 to 1975, when many hospitals closed the front doors as well, often in response to changing financial incentives and the need to cope with state budget problems (Morrissey, 1982a).

As people have been diverted and discharged from mental hospitals, in-patient and other services have diversified considerably, with a greatly increased role for the private sector (Kiesler and Simpkins, 1991). As in Britain, US general hospitals now play an important role in psychiatric in-patient care; in addition to hospitals with psychiatric units, extensive use is being made of 'scatter beds' in local hospitals without such units (Kiesler and Sibulkin, 1984).

In Britain, use of the old mental hospitals has declined steadily over nearly forty years. In England, the national in-patient census peaked in 1954 at 148,000, a year before the US peak. By 1974, the census had fallen to 104,400 (Audit Commission, 1986), and by 1989, there were some 58,900 psychiatric in-patient places remaining, of which 18,230 were in local hospital psychiatric units (Department of Health, 1991). In 1988, a survey of regional health authority (RHA) plans indicated that 33 hospitals were specified for definite closure, and an additional 30 for possible closure (Thornicroft, 1988). This policy was reaffirmed in 1991, when a Department of Health green paper called for a

> *[realignment] of the resources currently spent on England's specialist psychiatric services into district-based services, thereby allowing many of the 90 remaining large psychiatric hospitals to close by the turn of the century* (Cm. 1523, p.89).

In both countries, a need is generally recognised for some type of highly-staffed residential provision for a relatively small percentage of people for whom less intensive community approaches are inadequate. A still smaller percentage require secure provision on a temporary or long term basis. The numbers, characteristics and needs of this diverse population have been estimated variously, and there is considerable debate about the types of provision

1

COMMON FACTORS CONTRIBUTING TO DECLINING USE OF MENTAL HOSPITALS

Contributing factors common to both countries include the following:

- **Public concern about deteriorating conditions, neglect and even abuse within mental hospitals (See for example Deutsch, 1948; Robb, 1967; Morris, 1969; Martin, 1984);**
- **the drug revolution, making it possible to manage the symptoms of many mental disorders outside hospital (Taylor and Taylor, 1989);**
- **awareness of the disabling effects of long-term hospitalisation (Goffman, 1961; Wing and Brown, 1970);**
- **a growing body of research showing the benefits and affordability of treating and supporting people in their own homes and communities, using psychiatric hospitals as a back-up resource (Braun *et al.*, 1981; Kiesler, 1982; Anthony and Blanch, 1989; Freeman and Henderson, 1991);**
- **growing professional and government commitment to more flexible and modern forms of care (Joint Commission on Mental Illness and Health, 1961; Martin, 1984; Mosher and Burti, 1989; Marks and Scott, 1990; Bennett and Freeman, 1991);**
- **preference of patients and families for individualised non-stigmatising approaches, if adequately funded, dependable and responsive (Chamberlin 1988; Tanzman, 1990; Wills *et al.*, 1990; Ridgeway, 1988; Solomon and Marcenko, 1992);**
- **growing recognition by professionals and policy makers of the importance of consumer choice (Cm. 849, 1989);**
- **legal and judicial pressures to protect patients' rights, emphasising use of the 'least restrictive alternative', and limiting involuntary hospitalisation (Brown, 1985);**
- **pressures on health budgets, and the high costs required to bring old hospitals up to adequate building and staffing standards (Brown, 1985).**

that would be most appropriate and how best to meet their needs. At the same time, many professionals in both countries now agree in principle that treatment and support at home or in smaller, more homely settings is preferable to the use of large mental hospitals. According to this view, mental hospitals (or other psychiatric in-patient units) should function as a back-up resource to be used when community services or facilities are inadequate or unavailable (Warner, 1985; Mosher and Burti, 1989; Marks and Scott, 1990).

Comparisons of the deinstitutionalisation process in the US and Britain have been made by others (see, for example, Bennett, 1979; Thornicroft and Bebbington, 1990). For the purposes of this analysis, however, most interesting are the many common factors that have interacted in different ways on opposite sides of the Atlantic to create the shift away from mental hospitals (Box 1).

Gradually, it has been recognised that the patterns of neglect and the disabilities often attributed to 'institutionalism' can be found in many 'community' settings, as well as in mental hospitals. Nonetheless, policy makers and professionals are increasingly convinced that, on balance, long-term hospitalisation is both costly and inappropriate. This conviction and the other factors identified in Box 1, have combined with political and economic considerations about transferring responsibilities from one governmental level or sector to another. The result: a major decline in use of psychiatric hospitalisation for long-term care in both countries over the last four decades.

Parameters of change

There are certain obvious structural and political differences between the US and Britain which must be kept in mind when comparing approaches to mental health policy. In the US, state governments play a key role: mental health authorities, accountable to the governors of each state, plan and manage mental hospitals and related community services, paid for largely through state taxation, combined with various federal grants and entitlements. Many state mental health authorities have a considerable capacity for services development, 'technical assistance', programme monitoring and related functions. But state mental health policy and practice vary greatly, due to different organisational structures and to the interaction of federal, state and local laws concerning mental health and human services. State structures also vary for managing social services, income support, and housing although all states have an agency administering a vocational rehabilitation programme jointly funded by state and federal governments.

In some states, county or municipal governments play an important role in mental health care. Since 1985, with encouragement of a major foundation initiative, there has been a trend in major cities toward establishing local mental health authorities (Cohen and Shore, 1990).

The federal government influences state and local mental health policy directly through 'technical assistance', conferences, grants and contracts, and indirectly through various entitlement and reimbursement programmes under the US Social Security Act and other legislation. The National Institute of Mental Health (NIMH), part of the US Department of Health and Human Services, has for many years provided national leadership in mental health services development. Staffing and funding of these functions have fluctuated in accord with political decisions.

In 1992, the functions of NIMH in mental health service development were reorganised into a new government agency, the Substance Abuse and Mental Health Service Administration (SAMHSA), part of the Department of Health and Human Services. SAMHSA incorporates a new Centre for Mental Health Services. Whether these organisational changes will strengthen or reduce the federal leadership role remains to be seen. Meanwhile, the appropriate roles for national, state and local governments in mental health remain subjects of recurring debate in the US.

In general, however, mental health policy and provision have a considerably higher profile at all levels in the US than in Britain. In particular, the existence of a statutory body as a focal point for mental health at both state and national levels gives visibility to the US mental health enterprise.

In contrast, British mental health concerns are subsumed under broader NHS and community care policies. The leadership functions that have been undertaken in the US by NIMH are carried out in Britain in different ways by a range of statutory and independent bodies – the Department of Health, the Social Services Inspectorate, the Mental Health Task Force, the National Health Service Training Directorate, the Institute of Psychiatry, the National Centre for Mental Health Services Development at King's College, London, the King's Fund, Research and Development for Psychiatry, the Health Advisory Service, the National Mental Health Act Commission, Good Practices in Mental Health (GPMH), MIND and other national organisations, together with various management consultants operating in an increasingly competitive market. There is, however, no clear channel for co-ordinating such activities at a national level. The Department of Health and the Social Services Inspectorate perform many of the functions that NIMH has performed in the US. The nearest functional equivalent to a US state mental health authority is the mental health staff of a Regional Health Authority (RHA). Both RHAs and state mental health agencies are responsible for administering major public resources available for mental health services.

Some of these structural differences between the US and Britain have influenced policies towards deinstitutionalisation and care in the community, as discussed below.

Towards community treatment, care and support

By the mid 1960s, there was growing awareness among policy makers and the public in both countries that mental hospitals were becoming increasingly unsatisfactory. In both countries, policy makers were calling for better options. Since then, as the census of mental hospitals has been reduced, board and lodging costs have been transferred from health budgets to social security budgets, with a trend toward greater use of voluntary or private service provision in place of statutory provision. But in both countries, the gap between the rhetoric and the reality of community care and support has been immense.

The 'bold new approach' in the US

In an influential speech to congress on 5 February, 1963, President John Kennedy urged that

> *reliance on the cold mercy of custodial isolation ... be supplanted by the open warmth of community concern and capability.*

He called for a 'bold new approach' to address both mental illness and mental retardation, described as among the nation's most critical health problems. This would involve strengthening and improving programmes and facilities, which he said 'must be community-based'.

This led to a new community mental health centres (CMHC) programme. Federal support was offered to help communities provide 'five essential services': emergency, in-patient, out-patient, day care / partial hospitalisation, and consultation and education. These were to be planned and delivered with the participation of citizens of the local district or 'catchment area'. Since 1963, more than seven hundred such facilities have been established, covering about half the districts in the country, and greatly expanding access to mental health treatment by the general population.

What happened simultaneously, however, was a haphazard process of deinstitutionalisation, with mixed consequences for people discharged or diverted from mental hospitals, hospital staff, families and communities. While NIMH focused on developing the local CMHCs, it was mental health officials in each state who decided about hospital admission, discharge and service development policies, taking clinical, financial, political and other factors into account. Federal policies beyond the CMHC Act had a major and often unintended impact. Ernest Gruenberg has described the process like this:

> *In each state mental hospital, directors vied for a better report on a dropping census. The states began to compete with one another for publicity, with one*

> *claiming to have dropped its census more than another. A falling mental hospital census became a fetish and an end in itself, without regard for the consequences to the patients* (1982, p.277).

Hospital links with CMHCs, housing, social services and other agencies were generally weak. Readmission rates were high, and a 'revolving door' syndrome was becoming apparent. Despite the hope that CMHCs would replace state mental hospitals, evidence was accumulating that CMHCs were neither working with state hospitals, nor were they serving a high proportion of people who had been resident in such hospitals (Windle and Scully, 1976). Instead, they were serving a new clientele, many of whom would otherwise not have had access to mental health care.

The shift toward 'community care' in Britain

About two years before the US embarked on CMHC development, the Minister of Health, Enoch Powell, had announced a policy goal no less bold – 'elimination of by far the greater part of this country's mental hospitals as they exist today'. Like President Kennedy, he saw that 'few ought to be in great isolated institutions or clumps of institutions'. He also emphasised that

> *the transformation of the mental hospitals is not only a matter of buildings, the change of a physical pattern, it is also the transformation of a whole branch of the profession of medicine, of nursing, of hospital administration* (Powell, 1961).

The Hospital Plan of 1962 gave an outline of the intended transformation, but this was elaborated more fully in a 1975 white paper, Better Services for the Mentally Ill (Cmnd. 6233). Far more comprehensive than the CMHC concept in the US, the 'better services' concept calls for a full range of treatment, rehabilitation and support services linked with ordinary housing and employment for all who need mental health care in each district, as well as a focus on prevention. It remained the basic guidance on services design until 1993 and is further discussed in Part 3.

Since the 1960s, the mental hospital census has continued to decline steadily in Britain; in recent years, considerable numbers of less disabled patients have been released. Unlike the US approach, in Britain there has been an emphasis on 'reprovision' of mental health and related services for discharged patients; initial efforts to shift resources along with patients involved a dowry system. The 1970s and 1980s brought a policy emphasis on joint planning and collaboration between health and social services, with joint finance becoming available to enable social services departments to develop projects agreed upon with the NHS (Renshaw *et al.*, 1988).

The 1980s and early 1990s have seen the emergence in Britain of about 160 'community mental health centres'. Unlike their US counterparts, British CMHCs do not generally offer in-patient services. In the absence of governmental requirements as to essential services, there is great variation in clientele and service design (Sayce *et al.*, 1991a). As in the US, there are indications that British CMHCs are serving a 'new clientele', raising concern about actual or probable neglect of people with long-term needs. Of 67 CMHCs sampled in 1991, 90 per cent defined their clientele in very broad terms (Patmore and Weaver, 1991).

Information in Britain on the nationwide impact of community care policies on discharged patients, staff, families, and people diverted from hospital is fragmented and difficult to interpret. However, eleven demonstration projects on psychiatric rehabilitation, launched in 1981 (O'Callaghan, 1988), and eight pilot projects on care in the community for people with a mental illness, launched in 1983, have demonstrated the benefits of the community-based approach (Renshaw *et al.*, 1988; Knapp *et al.*, 1990). Equally promising are findings from major research on the process, costs and outcomes of resettlement and reprovision for patients discharged from Friern and Claybury hospitals (Leff, 1990).

Similar problems: caught in the crossfire

Despite growing evidence of the benefits of properly managed and funded 'community care', it is generally recognised in both countries that service development in the community has fallen short of needs. During the transition to a new style of care, service gaps and deficiencies have been widespread – often with devastating effects on individuals and families.

Early in the change process, it had often been assumed that living 'in the community' was inherently better than remaining in hospital. As the pace accelerated, however, so did public, professional and media concern about inadequacies in 'community-based' care. In the US, by the mid 1970s, the plight of the large numbers of people being diverted or released from mental hospitals without adequate support was widely considered a national disgrace (Aviram and Segal, 1973; Reich, 1973). An example of the rhetoric of the period was a report commissioned by a public employees' union entitled 'Out of their Beds and Into the Streets'. This report asks

> *how to explain a national non-policy on mental health that releases mental patients into community facilities that don't exist and protects their right to*

> *treatment by denying them publicly provided health services ...*
>
> *... 'deinstitutionalisation', a lofty idea, has become something very ugly – a cold methodology by which government washes its hands of direct responsibility for the well-being of its most dependent citizens* (Santiestevan, 1975, quoted in Turner and TenHoor, 1978, p.320).

In many cases, even for those former patients 'placed' in various residential settings, conditions were poor. One former patient living in a 'board and care home' in California wrote eloquently of problems in both hospital and community settings, arguing that for some, treatment 'in the community' may actually mean less real participation than a person would enjoy confined within an out-of-the community state hospital (Allen, 1974).

Most mental hospitals tried, with varying degrees of success, to arrange for accommodation and continuing psychiatric treatment for discharged patients. But medication and a bed alone were insufficient for people with serious and disabling mental health problems; most were poor, lacked friends, had few skills, and had great difficulty coping with ordinary life outside hospital. Stigma, discrimination and fragmented services added to their difficulties. Without reliable, continuing treatment and support, prospects for managing their difficulties or for finding friends, work or a sense of direction in life were minimal.

Often it was people most in need of such support who were least willing or able to find or use it, and little effort was made to reach out to those dropping out of services. Families, too, experienced extreme stress and distress in trying to provide homes for people who might in a previous era have spent long periods in hospital. Practical information, support and guidance were in short supply. Crisis support or respite care were often non existent, apart from rehospitalisation. And service providers often tended to blame families for causing the clients' problems, without even listening to the family point of view.

These concerns which became national issues in the US in the mid 1970s are similar in many respects to the concerns in Britain today. In both countries, as the old system erodes or is dismantled and efforts are made to create a new one, clients and families are likely to be caught in the crossfire. Types of problems most frequently cited are summarised in Box 2.

It is important to recognise that many current problems are inter-related. What happens in one part of the system often affects what is possible in other parts – even when the agencies involved do not think of themselves as participating in a

2

COMMON CONCERNS OF CLIENTS AND FAMILIES

As mental health and related services are being restructured, the following concerns are frequently stated in both countries:

- **few people admitted to hospital are offered any alternative. People continue to be inappropriately admitted to or retained in both acute and long-term hospitals because no suitable alternatives are available;**
- **the quality of treatment and environment in some mental hospitals has deteriorated. Even some general hospital acute units have become crowded and run down with little meaningful therapy – just medication or ECT, food and a bed;**
- **some people thought by their families or even themselves to need hospitalisation are not admitted for various reasons, yet are not offered adequate alternative help;**
- **self-neglect, self-harm, suicide or acts of violence sometimes occur among people who have been diverted or discharged from hospital without adequate support. (On suicide prevention, see Morgan, 1992; on violence, see Teplin, 1985 and Monahan, 1992);**
- **some people are 'placed' in semi-institutional settings 'in the community'; some are stigmatised, discriminated against, or neglected; and many lack affordable housing, work and social opportunities;**
- **many service users find available treatment or services insensitive, stultifying and disabling, with basic needs and personal concerns neglected through an emphasis on treatment alone;**
- **carers often lack information, guidance, crisis support, respite care, or an opportunity to be listened to;**
- **there are large numbers of people with mental illnesses among the homeless, many of whom are not being offered suitable housing assistance or relevant services;**
- **substantial numbers of people with mental illnesses are being held in unsuitable conditions on remand or in prison without appropriate treatment.**

Many of these difficulties can be attributed in large part to a single cause: inadequate development of locally-based opportunities and services, especially for people with disabling mental health problems.

system. For example, lack of access to affordable housing and support services contributes to 'bed blocking' in many acute psychiatric units. Some people remain in hospital because they have nowhere to go and others are not admitted, regardless of need, because of bed shortages.

Divergent philosophies also complicate efforts to assess problems and devise solutions. The same person in the same circumstances may be viewed in many different ways: as a victim of an economic recession, a harmless or irresponsible dropout from society, a person with anti-social behaviour, a person with an illness or disability, or as some combination of these. Each view implies different 'solutions'.

Underlying many of the problems in both countries is a lack of organised capacity within every district and locality to meet the full range of needs in the community. This includes not only mental health treatment and alternatives to hospitalisation, but also permanent, affordable housing linked to supportive services, occupational and social opportunities. Too often, housing shortages, fragmented responsibilities and inadequate resources make problems appear overwhelming, giving all concerned agencies incentives to pass the buck.

Similar policy debates: who should be responsible? who should pay?

By the mid 1970s in the US, such inadequacies in community-based care had become highly visible. At a national level, major analyses included critical reports by the US Senate Special Committee on Ageing, Sub-Committee on Long Term Care (1976) and the General Accounting Office (GAO), the investigative arm of the Congress (1977). The Senate report focused on ways in which changes in Medicaid and social security policy had led to 'transinstitutionalisation': thousands of former patients were being transferred from mental hospitals to proprietary nursing and boarding homes, many of them substandard. The report warned that such homes were emerging as a major industry which was becoming intractable.

The GAO is analogous in some ways to Britain's Audit Commission. The 1977 GAO report concluded that deinstitutionalisation had been adopted as a national policy in the US without adequate mechanisms to implement it effectively.

In Britain, by the mid 1980s, the shortcomings of US policies had become well known. By this time, the House of Commons Social Services Committee and the Audit Commission were calling attention to similar problems. Their respective reports (1985; 1986) examined causes for the disappointing pace of community service development and called for urgent action. Box 3 compares the GAO report of 1977 and the British Audit Commission report of 1986.

In 1986, the Audit Commission called for 'radical steps' to tackle underlying problems, including a rationalisation of central funding policies to create incentives for building up local authority community services. They also called for 'adequate short-term funding' to enable the transition to a new service pattern. The report expressed a sense of urgency, saying that:

> *the one option that is not tenable is to do nothing about present financial, organisational and staffing arrangements. Progress toward community care will continue to be slow; and the uneven pattern of services will persist* (Audit Commission, 1986, p.77).

In 1987, Sir Roy Griffiths was invited by the then Secretary of State for Health and Social Security, Norman Fowler, to advise on options to improve the use of public funds for community care. The 1988 Griffiths Report (which was not fully implemented), and the 1989 government white paper, *Caring for People* (Cm. 849), drew on the findings of earlier policy reviews and suggested partial solutions to some of the main policy problems.

The Griffiths ideas about community care developed alongside plans for a fundamental restructuring of the health service outlined in the 1989 white paper *Working for Patients* (Cm. 555). Ideas were brought together in the NHS and Community Care Act of 1990, which legislated sweeping changes in the way that health and social care were to be planned, purchased, provided and monitored. Central to the new policy is the requirement that both health and local authorities must separate the purchasing of health and social care from actual provision – diversifying what is on offer by contracting out with a range of voluntary and private providers. In the process, both the NHS and social services departments are encouraged to develop an 'enabling role'.

The NHS continues to be responsible for health care of people with a mental illness. But local authority social services departments (SSDs) are designated as lead agencies for social care for all the 'priority population groups' (people with mental illness, physical disabilities or learning disabilities, and elderly people). Lead responsibility for community care for people with a mental illness is being transferred from the nationally-financed health sector, available to all as an entitlement, to the social services sector, where services are means tested and are partially locally financed.

SSDs are expected to work with health authorities, housing agencies and voluntary and

3

SIMILAR POLICY PROBLEMS IN THE US (1977) AND BRITAIN (1986)

US GAO Deinstitutionalisation study (1977)

The GAO concluded that thousands of patients were remaining in mental hospitals principally because alternatives were undeveloped, while additional thousands were being 'placed' in inadequate 'community' settings. They cited the following contributing factors:

- **inadequate definition of service system goals, with an assumption that reducing the resident population of hospitals was an end in itself, not a means to an end;**
- **fragmentation and confusion of responsibility amongst many federal, state and local agencies;**
- **lack of authority of any single agency at any level to ensure that needs are assessed comprehensively, a system is planned to meet those needs, and quality of both institutional and community programmes is monitored;**
- **lack of a systematic approach to financing community-based services: resources not following patients into the community; shortage of start-up funds; incentives toward overuse of nursing homes; few incentives for local communities to accept responsibility;**
- **inadequate access of mental health clients to mainstream housing, vocational rehabilitation and social services;**
- **inadequate community organisation and advocacy for meeting the needs of people with long-term and disabling mental health problems;**
- **insufficient leadership at federal, state or local levels to move things forward.**

The Audit Commission report (1986)

The Commission concluded that despite some £6 billion being spent in England and Wales for services to 'priority groups', progress had been 'slow and uneven'. The following contributing factors were cited:

- **compartmentalised health and local government budgets, which hinder the needed shift in resources from health to social services;**
- **absence of bridging finance to facilitate the transition from institution-based to community-based care;**
- **the distorting effects of the public funding of private residential care, then running at around 1 billion per year and growing rapidly, through a process that provided perverse incentives for residential instead of domiciliary-based care;**
- **delays, difficulties and boundary problems caused by a fragmented organisational structure;**
- **the absence of staffing and training arrangements for community care, and inadequate means to ease the transfer of staff into the community.**

user groups in developing needs-led plans to deliver individualised 'packages of care' in the community. Since April 1993, all potential recipients of support for residential care must be assessed by SSDs, who manage the funding for their care. This is intended to encourage domiciliary support and to reverse 'perverse incentives' towards residential care. These policy changes, fully implemented in 1993, emerged from a debate lasting almost 20 years.

Clearly, the new policies and the use of contracting for services are stimulating fresh thinking about what needs to happen, and opening up new opportunities for action. But fulfilling the promise of these policies at local levels will be far from easy. The division of responsibility between health and social services remains a particularly vexed issue. Difficulties in distinguishing between health and social care, competing priorities, minimal past SSD experience in working with people with serious mental illness, and complex jurisdictional problems are among the issues likely to make system building difficult.

In addition, there is serious concern over whether available funding will be adequate (Ivory, 1993). Aside from modest 'pump-priming funds' through a specific grant, services for people with a mental illness have to compete for community care funding with the other priority population groups – a difficult proposition. A major shift in local government taxation policy from poll tax to council tax and an ongoing and major review of local government structures and functions add ambiguity to an already complex and ambiguous picture (Association of Metropolitan Authorities, 1991; Department of the Environment, 1991; Hudson, 1991).

Like the service deficiencies, the policy problems surfacing in Britain from the mid 1980s to the present have much in common with those identified a decade earlier in the US. In both countries, there have been particular problems about financing and division of responsibility. Major resources remain tied up in hospitals, and progress in reallocation has been limited. Extra transitional funding has been scarce, and mental illness remains near the bottom of many priority lists.

A related difficulty is co-ordinating resources for accommodation, social support, employment opportunities, income support and medical care outside hospital. Even when clearly entitled, mentally vulnerable people often find it difficult to gain access to benefits and services, and many find services currently on offer unhelpful. This requires advocacy, outreach and greater efforts to make services available in a manner and at times and places that are acceptable to people in need.

In both countries, analysts point to the absence of a coherent national policy for the care of people with a mental illness. Where goals are ambiguous, where funding and responsibilities are fragmented, there is a tendency toward piecemeal solutions and just 'muddling through' without much effort toward system building. The result: continued service inadequacies, blighting the lives of thousands of people with mental health problems and in many cases their families as well, and a massive waste of public resources.

In both countries, it is clearly necessary to continue the development of services in the community, despite the difficulties. That is not generally in question. At issue instead are questions about the philosophy that should guide the new pattern of service, the pace of change, the manner in which change comes about, who should be responsible for what, and who should pay.

Addressing these issues effectively requires a measure of shared vision among the many agencies and interest groups involved. Also needed is a coherent strategy and a sustained effort to mobilise collaborative efforts at every level toward planned, principled change. Part 2 describes a US initiative which has sought to address such issues from 1975 to the present – the NIMH Community Support Programme.

A sustained US initiative: the NIMH Community Support Programme

2

Three major cycles of reform ... the moral treatment, mental hygiene, and community mental health movements ... (have begun in the United States) with the promise that early treatment in a new setting would prevent the personal and societal problems associated with long-term mental disability ...

In each cycle, early optimism soon faded into despair over the increasing numbers of chronic patients considered incurable who began to accumulate in acute treatment settings

... In a number of respects the Community Support Programme defines a new fourth cycle of reform in the mental health field, aimed specifically at meeting the needs of the chronically mentally ill in community settings (Morrissey and Goldman, 1986, pp. 12, 13, 26).

In 1974, because of widespread concern about neglect of people being diverted or discharged from mental hospitals, the National Institute of Mental Health began reassessing its policies. In 1978, a modestly funded but significant systems improvement initiative was launched – the Community Support Programme (CSP) – a programme which continues in modified form at the time of writing.

Hallmarks of CSP include a new vision and service philosophy, a new systems approach to local planning, a new partnership between NIMH and state governments in developing local systems, strategic use of central funding to stimulate improvements at multiple levels and an emphasis on consumer, family and other stakeholder involvement. Stakeholder advisers helped design the programme. And a national 'stakeholder network' has met periodically at national and regional levels over more than fifteen years to identify lessons from experience and to guide policy and practice.

Some fifteen years after the initiative began, many problems remain with US services. However, the Community Support Programme has generated clarity and considerable consensus nationwide about service goals and strategies. It has also created a framework of ideas and working relationships within which improvements are being made, assessed and disseminated; this has been done by stimulating dialogue and mobilising collaborative action in every state.

This section describes the origins of CSP in the mid 1970s, focusing on how NIMH worked with stakeholders to create a new philosophy of services and a new concept for local planning. It also analyses the CSP strategy for promoting service improvement, concluding with an analysis of the programme's achievements and limitations.

The mid 1970s challenge: picking up the pieces

In 1977, the General Accounting Office (GAO) study of deinstitutionalisation found that 11 major federal departments and agencies were administering at least 135 programmes affecting people with mental disabilities (GAO, 1977). Similar fragmentation existed at state and local levels, making it easy to refer clients elsewhere, or to blame other levels or sectors for service inadequacies. Typically, mental health and welfare sectors blamed each other, as did local, state and federal officials. No single agency at any level viewed the situation comprehensively. Nor was any single agency responsible for assessing the full range of needs of people with psychiatric disabilities, planning and developing a system to ensure that needs were met and monitoring quality in both institutional and community programmes.

At a national level, NIMH was seen as responsible for mental health policy. Providing national leadership was difficult, however, given that NIMH did not control the major part of the resources going into mental health services. The 1977 GAO report specifically commented that NIMH

> *controls only a small proportion of the funds needed for deinstitutionalisation [and community support], exerts only a limited influence and no authority over other agencies, and has neither authority nor responsibility for monitoring, evaluating and enforcing standards or requirements under other programmes serving the mentally disabled* (GAO, 1977, p.36).

NIMH's annual services budget was small in comparison to federal entitlement programmes or state mental health budgets. With its own funds almost entirely committed to local CMHC construction and staffing, NIMH had little influence on the policies of state mental health agencies. In addition, NIMH's relations with state mental health agencies had been strained by an earlier policy decision to develop CMHCs directly, bypassing state governments. And the influence of NIMH on other human service agencies whose programmes were important to people with mental health problems was even more limited. Nonetheless, as the urgent need for national leadership became apparent, it seemed incumbent upon NIMH to take the lead. It was also becoming clear that any effective national strategy would have to find ways to influence many agencies, key actors and resources outside the direct authority or control of NIMH.

A new guiding vision: community support and rehabilitation

The philosophy, concepts and strategy of community support were developed through an extensive participatory planning process. An internal NIMH 'community support work group' began examining the issues in 1974. Between 1975 and 1978, eight small national working conferences were held to synthesise differing stakeholder perspectives. This consultative process shaped the vision and philosophy for the programme launched in 1977/78 (Turner and TenHoor, 1978).

The early working conferences focused exclusively on clarifying and elaborating the vision of what needed to happen at local levels, temporarily setting aside questions of how best to make it happen. This emphasis on the importance of a clear and widely shared vision has come to be regarded as a key ingredient in the achievements of the programme (Mental Health Policy Resource Centre, 1992).

The initial vision of CSP planners and advisers was to create local systems of support for people who did not need to be in hospital, but who needed extra support to manage on the outside. They wanted to make it possible for every citizen with a disabling mental health problem to have access to flexible and reliable services and opportunities appropriate to their needs. Those most disabled and vulnerable were seen as first priority for publicly funded service provision, a major departure from the CMHC emphasis on prevention and universal access to mental health care.

After considerable debate, agreement was reached on ultimate and intermediate goals for a national initiative. The ultimate goal was 'to improve the quality of life' of adults with long-term and disabling mental health problems. The intermediate goal, or means toward the ultimate goal, was 'to stimulate and assist states and communities to develop comprehensive community support systems (CSSs)'.

The focus on 'improving the quality of life' was preferred to a focus on improving treatment or services or functioning. Mental health treatment alone was clearly insufficient; ordinary needs for income, housing, and work, as well as social, family and crisis support, were equally important. And instead of locally-based community mental health *centres*, CSP, which operated parallel to the CMHC programme for some time, was seeking to create community support *systems*, within which CMHCs and other service providers would play a role, working in partnership with consumers (users), families and community groups (Turner and TenHoor, 1978).

The term 'community support' was deliberately chosen in preference to 'community care'. The aim was to avoid implying a passive, one-way relationship based on a sharp distinction between the carer and the cared *for*. Instead, CSP planners emphasised the need to create conditions in which recipients of treatment and support would be strengthened in their own abilities to care – not only for themselves, but also for others.

CSP planners also re-examined other aspects of service philosophy, listening to family and consumer leaders and providers of innovative services about what mattered most. In the process, terms such as 'after-care', 'day-care' and 'half-way houses' were seen to have limited value. After-care suggested that the real care took place in hospital, no longer a valid assumption. Most approaches to 'day-care' kept people in the role of patient or client, unsatisfactory over the long-term. Time-limited service approaches were seen as problematic for people with long-term needs. Half-way houses, for example, raised the question: 'Half-way to where?'.

Most people with mental health problems, like everyone else, were seen as needing permanent, affordable homes along with appropriate and flexible medical treatment and social support. Additional themes were 'more being with, and less doing to', 'more real work, less make-work', and the need to develop 'opportunities as well as services'. In these and other ways, the emerging vision contrasted with prevailing approaches.

In addition to views of stakeholder advisers, the new philosophy drew on research and on a wide range of perspectives. Significant influences included: consumer concerns articulated by a Californian ex-patient (Allen, 1974); an illuminating philosophical reflection on the dynamics of caring and being cared for (Mayeroff, 1971); concepts of personal support systems (Caplan, 1974); the principle of normalisation (Wolfensberger, 1970); and certain exemplary local services or 'model programmes'.

Mary Ann Test's and Leonard Stein's approach to treatment in natural settings, including an emphasis on 'assertive outreach,' was particularly influential (1976, 1978). Equally influential was the clubhouse model (sometimes known in the US as the 'psychosocial rehabilitation' approach), pioneered by New York's Fountain House. This emphasised the need to create valued and productive roles and a sense of belonging for people with psychiatric disabilities. (See the special issue of the *Psychosocial Rehabilitation Journal,* 1992, for a full elaboration.)

The limits of 'model programmes' have since been well articulated (Bachrach, 1980). However, many such programmes exemplify principles that are relevant to any setting. The programmes listed in Box 4, some of which are still in operation nearly twenty years later, influenced CSP philosophy, and have inspired developments along similar lines throughout the US, stimulated in part by the CSP initiative.

4

'MODEL PROGRAMMES' THAT INFLUENCED US COMMUNITY SUPPORT PHILOSOPHY

- ***The Programme of Assertive Community Treatment (PACT)* pioneered in Madison, Wisconsin, provides intensive treatment and support from a multidisciplinary team as an alternative to hospitalisation (Test and Stein, 1976; 1978).**
- ***Fountain House* in New York City and other community rehabilitation clubs create useful roles for members, a context for making friends, and support for working and living in ordinary settings (Peterson, 1982; Beard *et al.*, 1982).**
- ***Soteria House* offered a non-hospital alternative for people experiencing symptoms of serious mental illness (Mosher *et al.*, 1975).**
- ***Crisis foster care,* pioneered in Denver, enlisted, trained and paid ordinary families to provide temporary refuge for acute patients, with professional back-up (Polak and Kirby, 1976; Polak, 1978).**
- ***Places for People,* developed by a British psychiatrist at St. Louis State hospital, provided an extensive network of supportive housing, work and social opportunities and services (Sandall *et al.*, 1975).**
- ***'The Lodge'* approach enables long-term residents of mental hospitals to live and work permanently in group settings independent of professionals (Fairweather *et al.*, 1969).**

From vision to concept: community support systems (CSSs)

To promote community support systems, NIMH found it necessary to define them clearly. This led to development, in consultation with stakeholder advisers, of a new planning concept. The CSS concept was designed to provide detailed, yet flexible guidelines about what needed to happen at local levels.

CSP planners thought that the idea of a community support system could be usefully elaborated for any vulnerable population with special needs. However, they focused initially on clarifying the full range of needs of one clearly defined population:

> *severely mentally disabled adults whose primary disability is emotional and for whom long-term 24-hour nursing care is inappropriate* (Turner, 1977, p.1).

Despite debate about whether 'the chronically mentally ill' 'belonged' in well-run hospitals or institutions, CSP planners were convinced from research, model programmes and stakeholder consultation that better options were both desirable and feasible for most. To develop such options required clarity about what 'worked' and was actually wanted or needed. As a basis for planning, they began by identifying certain functional characteristics of the population of concern (see Box 5).

CSP planners agreed however, that the population of concern was only *partially* disabled. As individuals, they have diverse interests, competencies and strengths, which can be enhanced. These individual motivating factors needed to be given great emphasis in planning opportunities and services, avoiding the tendency to over-emphasise symptoms, problems and deficits.

In defining the essential functions of a community support system, NIMH and its stakeholder advisors deliberately deferred the questions of who should be responsible and who should pay for each service component. Instead, they looked at the situation as if all existing and potential resources for meeting those needs were

5

THE 'POPULATION OF CONCERN' FOR THE COMMUNITY SUPPORT PROGRAMME

The 'CSP population' were seen to need special attention because they tend toward the following characteristics – either intermittently or for long periods:

- **they have had or are likely to have recurring or sustained contact with the mental health system;**
- **they tend to lack of self-confidence and self-esteem, and are extremely vunerable to stress;**
- **they are likely to have difficulty with basic daily living tasks;**
- **their capacity to work on regular jobs may be limited by under-developed skills, vulnerability to stress, and stigma and discrimination;**
- **they often lack money for adequate food, clothing and shelter;**
- **they are likely to be unable at times to seek out and enjoy leisure activities and may become isolated;**
- **their relationships are strained by what others experience as extreme dependency and strong and sustained demand for tolerance of odd behaviour and idiosyncratic activity;**
- **despite medical treatment, they may have atypical experiences, disturbed thinking, and episodes of behaving in ways that interfere with their own well-being and that of others;**
- **they often find available services unhelpful, and may seem to lack either ability or motivation to seek help from or sustain contact with workers in human service agencies.**

Adapted from Turner (1977), *Comprehensive community support systems for severely mentally disabled adults: Definitions, components, guiding principles,* National Institute of Mental Health, Rockville, Maryland, USA.

amenable to influence in one way or another. As a result, the CSS concept extends beyond the boundaries of responsibility of the mental health system. This open systems approach emerged as a key feature of the CSP initiative. Figure 1 summarises the 10 essential system components (later expanded to 11) required to support the CSP population in each locality. (See Turner and Shifren, 1978 for the rationale behind each component; see Stroul, 1988 for update.)

Box 5 and Figure 1 illustrate in different ways the CSS focus on people and service functions, rather than on facility or agency types. For example, instead of aiming to create more community-based in-patient units or more day hospital places, the CSS concept focuses on underlying purposes of such activities. The essential functions (called components) can be provided in a variety of settings by a variety of agencies.

NIMH revisions to the concept, in 1980 and 1988, have brought new emphases based on experience. These include the necessity to plan for transport as an aspect of outreach; the importance of both residential and non-residential options for crisis stabilisation, including in-patient services when necessary (Stroul, 1987); the advantages of flexible support services, helping people choose, find and keep long-term housing and work, in contrast to assuming they must move as their condition changes (*Psychosocial Rehabilitation Journal*, 1987; 1990). Another shift has been recognition of the need to organise family education and support as well as consumer and other self-help groups in every geographical area. Both family and 'peer support' are now seen by NIMH as essential, rather than as 'optional extras' (Stroul, 1988).

At the centre of the CSS are the individuals experiencing mental health problems, their families and friends. The system as a whole should function as a resource to strengthen their coping abilities. Indeed, a CSS is intended as more than a system of services. It is equally intended as a network of opportunities, a blend of formal and informal helping systems, purposefully nurtured and developed by public planners and providers, working in partnership with a vulnerable population, their families and friends. Community development functions are critical to creating and maintaining community support systems.

In addition to identifying a population of concern and assessing their needs NIMH guidelines also called for a 'core services agency' to provide district-wide leadership in CSS development, and a single person or team at a client level to provide continuity and to ensure access to various necessary services and opportunities. The core services agency could be a unit of local government, a hospital, a community mental health centre, an independent rehabilitation centre, or some other body – as long as the state and the local area could agree.

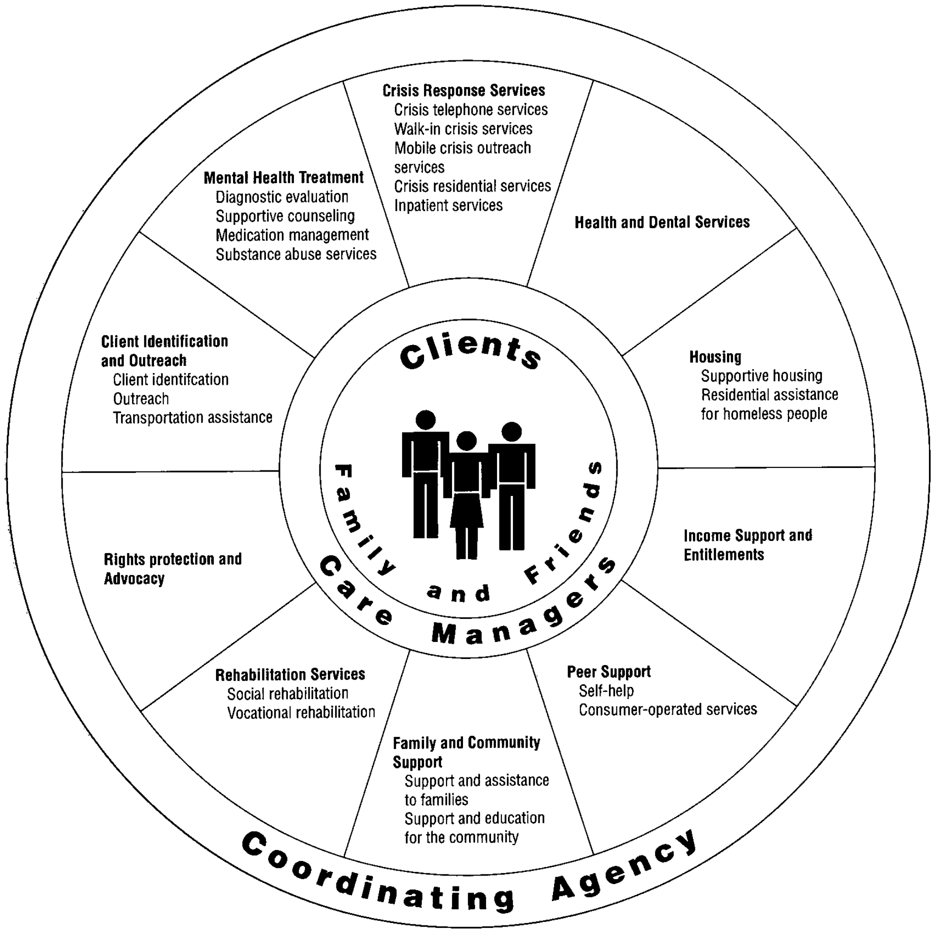
Precisely which type of agency should provide which CSS components was also left for state and local decision. This was intended to encourage local CSSs to develop organically – in accord with local geography, economy and culture – making best use of resources, facilities and leadership available. When several CSS functions were provided by a single agency for a particular sub-group of the population, this was regarded as

Figure 1 The Planning Concept: a community support system

THE PLANNING CONCEPT: A COMMUNITY SUPPORT SYSTEM

'An organised network of caring and responsible people and organisations committed to helping a vulnerable population meet their needs and develop their potential ... in the community.'

Turner and Shifren 1978, p.329



Essential Functions of a 'CSS'

NIMH guidelines specified ten essential functions that should be planned for in every district to meet the needs of 'the CSP population'. The list above reflects revisions made in 1988 based on ten years of experience and outreach.

Source: Adapted from Stroul (1988) *Community Support Systems for Persons with Long-Term Mental Illness: Questions and Answers,* National Institute of Mental Health Community Support Programme Office, Rockville MD, USA.

a 'community support *programme*'. Only if efforts were underway to develop all ten components throughout the district did the term 'community support *system*' become appropriate.

The strategy: mobilising concerted efforts in every district

While the CSS concept focused on direct service functions considered essential in every district, the CSP strategy specified service development activities to be carried out by state mental health agencies, working in partnership with NIMH. The main ideas for the strategy were developed through consultation with stakeholder advisors in 1977, building on the idea of developing local 'community support systems' nationwide. The strategy was launched in 1977/8, by redirecting just under $5 million of NIMH funds that had previously been allocated for improving state mental hospitals.

The strategic question for CSP planners was how such a small amount of discretionary money could be used in a way that would make a difference in the lives of significant numbers of the CSP population. At this point, it had been estimated that there were some 1.5 million people meeting NIMH's functional definition of the 'CSP population' (Minkoff, 1978). They were living in 50 different states, in 1,500 planning districts, of which only about half had federally assisted community mental health centres. The CSP therefore evolved as a 'programme of influence,' seeking to have a multiplier effect, by exerting leverage over activities and resources of state mental health authorities and other state and local agencies.

The central idea was to use NIMH's limited resources to 'stimulate and assist' state mental health authorities to assume leadership in CSS development. More specifically, these authorities would be assisted to develop and carry out their own detailed strategies, to refocus their own activities and seek to influence other state and local agencies. State projects would be carried out in the context of related national level activities: project monitoring and technical assistance; interagency work; conferences; evaluation and research. All this would be harnessed towards the ultimate goal of improving the quality of life for the population of concern. Figure 2 summarises the development strategy.

Late in 1977/78, 30 states applied for CSP funding, and 20 pilot projects were approved for the initial year of a five year process of CSS strategy development, implementation, and evaluation. Eleven of these included local CSS demonstration projects as part of an overall state strategy. Of the ten states that were initially unsuccessful, several later launched CSP initiatives with their own funding.

By 1983, all states were participating in the Community Support Programme. Since then, the mission of the programme has remained constant, but the strategy has been altered in consultation with stakeholder advisors, and in response to political decisions, with a shift in recent years towards 'research demonstrations'.

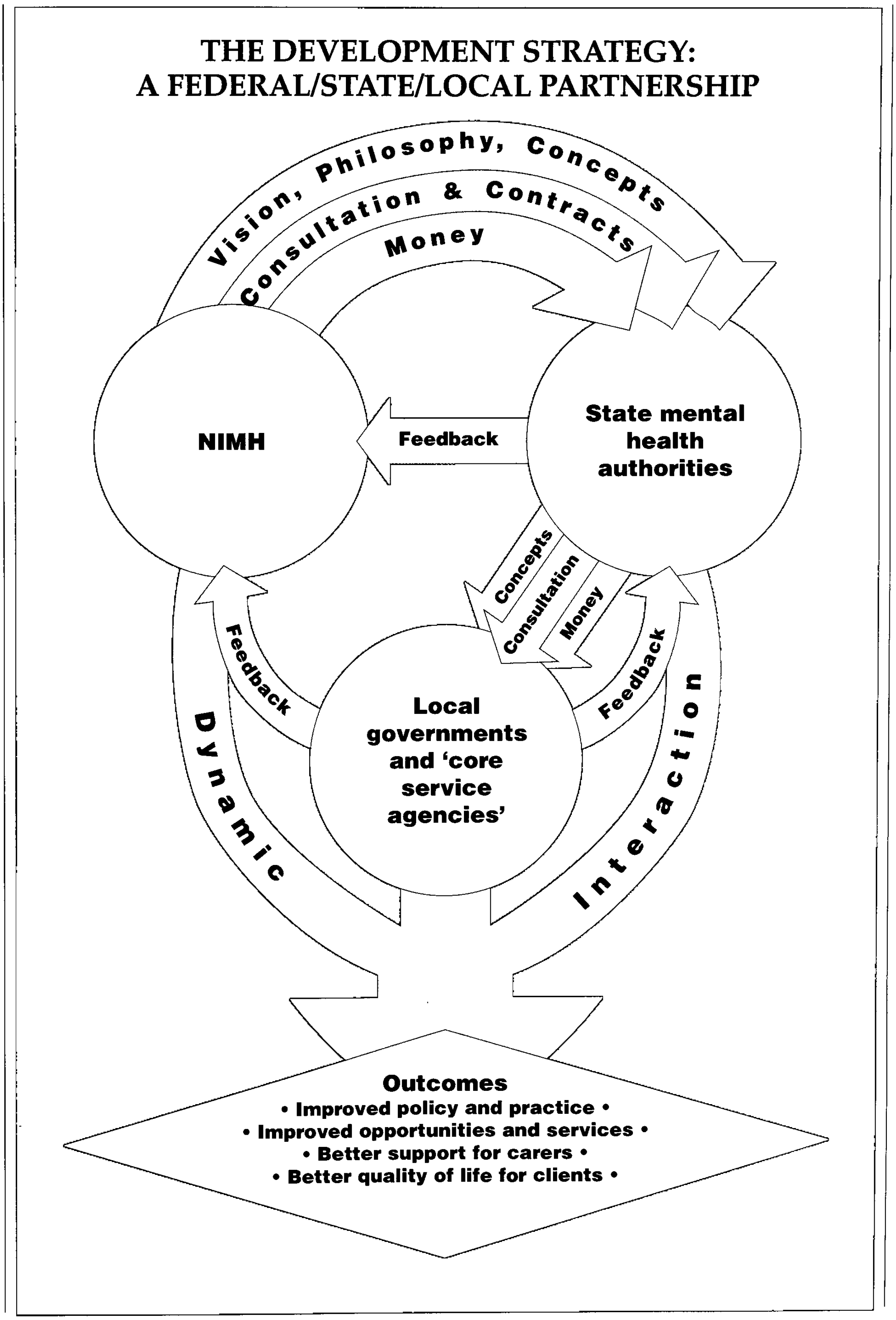
The pages that follow analyse and describe five main elements of the strategy during the pilot phase, focusing on aspects that are relevant in the British context. These are:

- mobilising leadership for systems development and improvement, through a partnership between central government and state mental health authorities;
- incentives and 'leverage' for systems change, including technical assistance, consultation and 'performance contracts' requiring states to perform developmental functions;
- mobilising 'mainstream' resources for housing and work opportunities through national interagency collaboration;
- orchestrating a nationwide stakeholder network to promote cross-boundary collaboration, sharing of lessons from experience, and concerted action in every state;
- harnessing research and evaluation as a means for system development and improvement, through collaboration between researchers and other stakeholder groups.

Leadership for systems change

A fundamental policy question in designing the new initiative was deciding on NIMH's main partners in implementing CSP goals. Despite previous strained relationships between NIMH and the state mental health authorities, their long experience with the CSP population was a potential asset. As in Britain, US mental hospitals had launched many pioneering community programmes, although by the mid 1970s these had gone out of fashion and received little national attention. Another argument for a new partnership with state mental health agencies was their control of substantial resources for the care of those with serious mental illness. Through working with those controlling the vast sums tied up in mental hospitals there would be a greater chance of redirecting these resources along more productive lines. In addition, as mentioned, CSP planners wanted their limited resources to have a multiplier effect. Funding a few local projects directly would be unlikely to have much nationwide impact. Working through state mental health agencies, however, offered the potential for influencing all

Figure 2 The development strategy: a federal / state / local partnership



areas of a state, as well as 'mainstream' state agencies whose participation was essential to achieving CSP goals.

NIMH, therefore, took a stand: although state mental health agencies did not directly control all the community resources needed by people with long-term mental illness, the mental health sector had a moral responsibility to assume leadership in ensuring that the comprehensive needs of this population were met.

In 1977, a draft CSP proposal was widely circulated to stakeholder advisers and to all state mental health authorities for comment. In this way NIMH hoped to bridge the communication gap and pave the way for a genuine partnership with the states. The proposal was well received and Congressional approval was obtained.

The policy stand encompassed in the new initiative shifted the dialogue from 'who is to blame for the fact it is not happening' to 'what are the steps required to start actually making it happen?'. This approach also enabled NIMH to identify and support a network of 'change agents'. Inclusion of 20 states in a pilot programme, described below, provided a critical mass for the intended multiplier effect.

Incentives, contracts and support

Funds available from NIMH's Hospital Improvement Programme had typically been used to encourage local innovation, which could be adapted to other localities. CSP planners, however, took a different approach. Instead of using demonstration funding for provision or improvement of local services, they sought to use it to stimulate and support a nationwide process of systems change.

In the pilot phase of CSP (1978-1983), states were offered an opportunity to compete for two types of projects, both directed toward systems change. One type focused on statewide strategy development through a participatory planning process; the other focused on demonstrating the CSS idea in particular localities. CSP funds could be used for filling service gaps, improving co-ordination, changing the style of services, and otherwise transforming reasonably well-developed local networks into well-defined, responsive district-wide systems. Appropriate uses for CSP funds included studying, evaluating or spreading service concepts. However, service provision was to be funded mainly from the usual sources, in keeping with what could be expected in an average district in that state. These requirements were designed to increase the likelihood that any good ideas being demonstrated would be useful in other localities as well.

The main idea underlying the design of the pilot programme, however, was leverage. CSP planners and advisers were convinced that without clear targeting and direction, the limited funds available for the initiative would have little impact on massive state service systems. Stakeholder advisers emphasised that there was little point in a new partnership with states unless NIMH was going to take an active role. This led a state mental health commissioner to suggest that NIMH use the highly prescriptive mechanism of 'performance contracts' as a way of achieving the needed leverage for change.

Contracting was already being practised by some state mental health authorities as a means for purchasing local services; contracts were a useful mechanism for CSP purposes because they specified what should be done, how it should be done, by when, and how progress would be measured. This enabled NIMH to develop very precise requirements. The contracts were intended as an incentive to states for strategic planning and CSS development, helping them get beyond 'muddle through' approaches to long-term mental illness. The contracts specified the population of concern, the planning concept to be used, the planning approach to follow (maximising stakeholder involvement), and a number of 'CSP development tasks' for which funds were to be used. The tasks summarised in Box 6 were elaborated as part of contract requirements.

Strategy projects required stakeholder involvement in a three year state-wide plan to develop CSSs in all localities. Demonstration projects focused on specific local districts, developing exemplary CSSs to energise a statewide CSS development. Many of the requirements had been recommended by stakeholder advisers representing those who would have to implement the projects. Nonetheless, they were arduous for such a small amount of funding. NIMH even required quarterly reports for the first year, with the intention of capturing lessons from experience.

Contract requirements were flexible, however, in some respects. As mentioned, the core service agency role and other local organisational arrangements were determined by each state. Criteria for identifying the CSP population were also somewhat flexible, providing that clients met the broad functional definition of the CSP population, a decision that has complicated later efforts to make cross-state comparisons (Schinnar *et al.*, 1990).

Leverage for change came about in several ways. First, through competition for the contracts, and the stringent application requirements and funding criteria. Indeed, that process alone stimulated states to focus on the CSP agenda. Second, in awarding the initial contracts, NIMH required some states to modify their plans to improve chances of success. For example, some states were asked to give the CSP project director, the key 'change agent', greater authority and scope. Third, continued funding depended on satisfactory performance of contract tasks. These were standard for the first year, and were negotiated between NIMH and the state for subsequent years.

During the pilot phase, national CSP staff made periodic visits and tried to help projects achieve their goals and tasks, working in a spirit of partnership. These visits often helped bring together key mental health officials as well as those from other agencies that shared responsibility for community support, clarifying aims and strategies. NIMH project officers also promoted stakeholder involvement, especially encouraging consumer participation in planning and policy.

The role of an outside convener and catalyst was regarded as a key ingredient in the partnership. CSP managers were convinced that even in states where leaders clearly wanted to achieve CSP goals and understood what needed to be done, some kind of 'clout' from outside the system was often useful in raising critical questions or overcoming resistance to needed system change.

Mobilising 'mainstream' resources: national interagency work

To help states mobilise mainstream resources, NIMH acted as an advocate with federal agencies concerned with housing and employment. For example, CSP staff worked at a national level with the Rehabilitation Services Administration, a statutory body, to develop a formal co-operative agreement. This identified shared goals and spelled out how state mental health and vocational rehabilitation agencies could best work together. It led to numerous follow-up activities: many states developed similar agreements, and the two agencies jointly funded four Research and Training Centres in Psychiatric Rehabilitation.

In 1977 and 1978, CSP staff helped to stimulate the federal Department of Housing and Urban Development (HUD) to develop a joint effort, the HUD / HHS Demonstration Program for the Chronically Mentally Ill. Despite many bureaucratic obstacles, this created new housing opportunities for substantial numbers of people, and paved the way for further developments throughout the 1980s and into the 1990s (Macro Systems Inc., 1982; Levine and Rog, 1990).

Some commentators on CSP have questioned how much can be achieved through interagency collaboration; they have noted, however, that CSP's multi-level approach was somewhat more promising than prior approaches (Morrissey, 1982b). Despite difficulties in such efforts, it seems clear that any contemporary approach to psychiatric disabilities will require effective links among many organisations. The effort to collaborate cannot be abandoned, no matter how frustrating it may be at times. To put such efforts in perspective, one researcher has noted that:

> *it is only from the combination of adequate resources with effective organisational arrangements that we can reasonably expect improvements in the quality of life ... to be obtained* (Morrissey, 1982b, p.115).

In many cases, collaboration alone is not enough; fundamental structural and financing changes may be required. The necessity for such changes became the theme of a major US foundation initiative on chronic mental illness launched in 1985 (Shore and Cohen, 1990; Goldman *et al.*, 1992).

6

DEVELOPMENT TASKS CARRIED OUT BY STATE MENTAL HEALTH AUTHORITIES

Contracts required state mental health authorities to assume the following leadership functions:

- **mobilising the mental health system by designating a highly placed 'change agent' and staff to redirect policies and programmes toward CSP goals;**
- **identifying the CSP population and assessing their needs comprehensively, consulting stakeholder groups;**
- **identifying existing and potential resources from the mental health system, other human service agencies, and the community that could be better used to meet CSS needs;**
- **working with other state health and human service agencies to increase access to mainstream resources;**
- **developing a broad-based stakeholder constituency, and promoting new groups of consumers and families;**
- **developing local CSS demonstrations and components, in a way that would stimulate similar developments elsewhere;**
- **providing technical assistance, consultation and training to local programmes;**
- **documenting and evaluating activities to identify problems encountered and lessons learned.**

The network: creating a culture of innovation

A pillar of NIMH's strategy was what came to be called the 'CSP Learning Community'. This long-term series of national, regional and state stakeholder conferences and other networking activities has energised the change process in many ways, and has provided a forum for clarifying and disseminating lessons from experience.

During CSP's pilot phase, a format evolved for large scale national conferences that brought together, in approximately equal proportions, representatives of the following stakeholder viewpoints:

- consumer leaders (service users);
- leaders from family organisations;
- managers and professionals involved in local service systems or innovative projects;
- state programme managers or policy makers, including mental health commissioners;
- national mental health, housing and social welfare officials and leaders from national organisations;
- academics concerned with research, training and evaluation.

These groups, sometimes referred to as 'peer groups', guided the CSP change process. At an early stage, special efforts were made to include people from ethnic minority groups in the main groups; eventually they also began forming a minority caucus at various meetings and conferences.

Stakeholder conferences reinforced the participatory approach built into state CSP contracts. State mental health authorities were required by their contracts to identify and consult with all the main stakeholders who shared responsibility for mental health, housing and support services to the CSP population – creating 'coalitions of concern'. In addition to involving existing groups, state mental health agencies were expected to help develop new consumer and family groups where none existed. Project funds were intended to support such developmental activities. At first, the idea that 'consumers' of any sort could contribute to mental health policy making at all was relatively new, both to states and to NIMH staff. It soon became NIMH policy, however, to recognise that both 'primary' and 'secondary' consumers need to be heard, and that one could not represent the other.

Because stakeholder conferences proved so useful in furthering the entire strategy, by 1979, NIMH began organising national conferences nearly every year. Later, regional conferences were organised along similar lines. Each conference was carefully structured to achieve multiple purposes as outlined in Figure 3.

The conferences offered consumers and families a context within which to organise, a platform for expressing their concerns, and opportunities to learn about how to change 'the system'. Within the CSP network, the national influence of both primary and secondary consumer organisations has greatly increased (Chamberlin *et al.*, 1989).

State and local managers and professionals facing difficulties or resistance to change found new perspectives, moral support and advice, and reinforcement for consumer-oriented values. 'Technical assistance' was offered on a mutual help basis, through peer support networks developed through the conferences. CSP managers welcomed the opportunity to fine-tune their policies based on input from the field. Interagency work was encouraged by inclusion of relevant agency officials in the network, helping to build the mutual understanding and sense of common purpose required. Researchers, too, gained from interaction with consumers, managers and policy makers. Research questions relevant to policy and practice were identified, and multi-state collaboration was enhanced. New methods were developed for doing research in partnership with users and families. And closer dialogue with intended users of research findings helped to narrow the gap between research and practice.

The conference series has continued for fifteen years, allowing ideas to be developed, tried out, discussed, and refined. National and regional conferences have been supplemented by a newsletter, the *CSP Network News,* published quarterly by Boston University. As the network has gradually expanded, conference designs have been modified. The ethos and dynamics of interaction have remained much the same – if anything, more vital as participants have become better informed, knowledge has increased, and growing numbers of consumer and family leaders have contributed their experience.

The 1983 conference illustrated the participatory process by inviting 'peer groups' to focus two working sessions on identifying priorities for future collaboration. Despite their differing backgrounds and orientations, groups of consumers, families, managers, policy makers and researchers were able to reach consensus on the following goals as for the next decade:

- create a comprehensive community support system in every district in the US;
- create and fund ex-patient/consumer defined, run and controlled alternatives in every state, and establish a national network for planning these with grassroots input;
- develop a national network, analogous to and linked with CSP, directed to CSS for children and adolescents at high risk, for the purposes of prevention and early intervention;
- develop new knowledge about how to achieve goals, using broad consumer input to research planning and priorities, and increase research funding (Boston University, 1984).

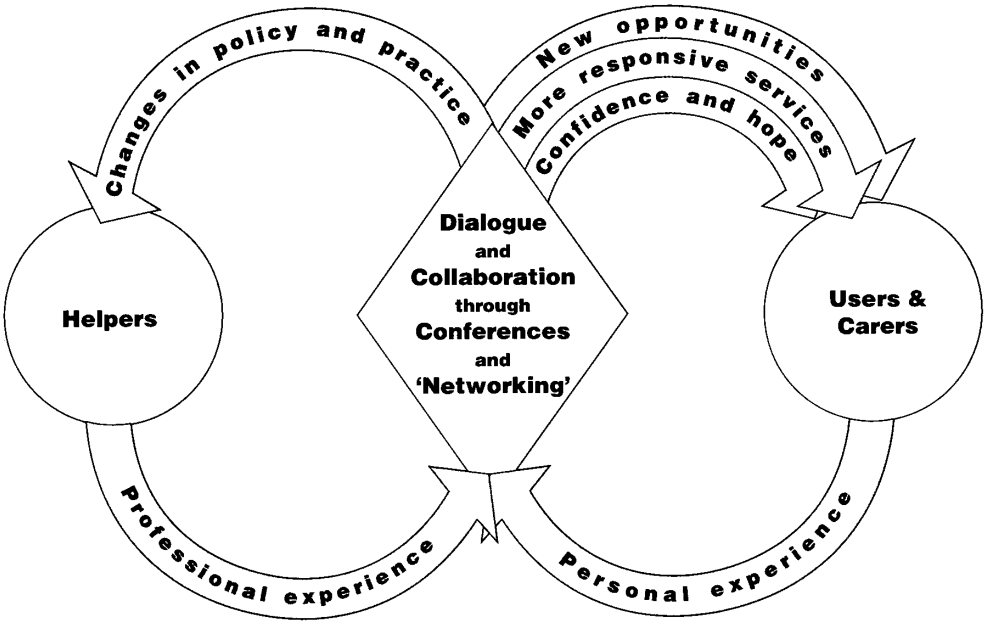
In the decade that followed, each of these goals was actively pursued (Brown and Parrish, 1987;

Figure 3 The stakeholder network: a culture of collaboration

THE STAKEHOLDER NETWORK: A CULTURE OF COLLABORATION

The CSP 'stakeholder network' brought together over a period of years balanced representation from all the main stakeholder groups to achieve the following goals:

- **to share information on important developments, problems and opportunities;**
- **to share perspectives on what was and was not working, and why;**
- **to develop joint strategies for collaborative action at each level and across levels to move things forward.**



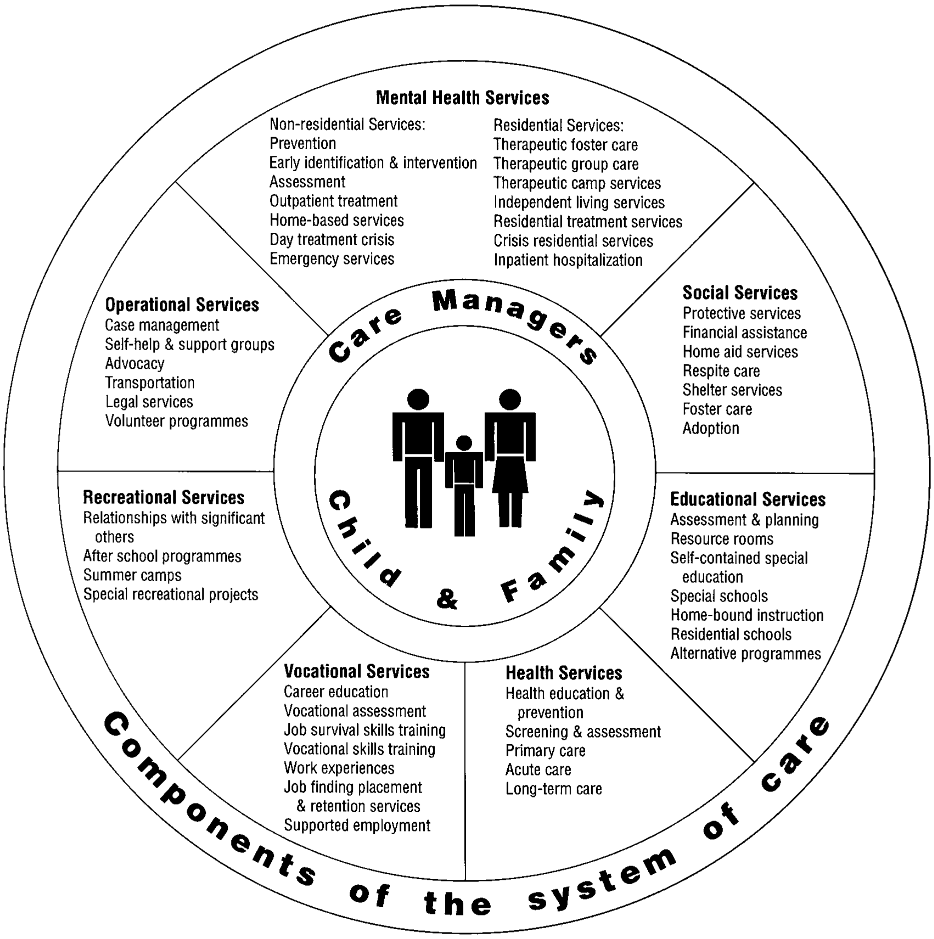
More specific objectives included:

- **clarifying and refining vision and values;**
- **strengthening opportunities for service users, ex-users, carers and minorities to influence decision making;**
- **developing, supporting and empowering leaders from all stakeholder groups, and encouraging good practice and innovation;**
- **identifying policy problems and solutions, and highlighting policy changes needed at each level;**
- **promoting collaborative evaluation and research;**
- **facilitating dialogue and joint action across boundaries.**

Based on NIMH, (1982) and Boston University, (1983; 1984; 1987; 1989), ***A Network for Caring: Proceedings of National CSP Learning Community Conferences.*** **Conferences 1-4 published by NIMH, conferences 5-8 published by Boston University.**

Figure 4 A spin-off of CSP: the Children and Adolescent Service System Concept

A SPIN-OFF OF CSP: THE CHILDREN AND ADOLESCENT SERVICE SYSTEM CONCEPT



In 1985, NIMH launched an initiative to promote systems of care for children and adolescents. This figure, showing the components of such systems, is adapted from B. Stroul (1988), *Series on Community-Based Services for Children and Adolescents who are Severely Emotionally Disturbed*, Vol. 1, Georgetown University Child Development Centre, Washington DC, USA.

Parrish, 1991). Although the CSP initiative has shifted in recent years toward a focus on well defined 'research/demonstrations', CSP development in every state has remained a major goal. Consumer-controlled demonstration projects have been funded in some 25 states. In 1984, NIMH began funding annual national consumer 'Alternatives' conferences. Later, periodic national consumer teleconferences were launched, as well as a satellite cable television project to link consumers throughout the country. In addition, in 1985, NIMH launched a nationwide *Children and Adolescent Service System Programme* modelled on CSP (Stroul and Friedman, 1986) – see Figure 4. NIMH services research, too, has shifted toward CSP issues.

The stakeholder network has also influenced wider national mental health policy: the *Mental Health Systems Act* (1978), the *National Plan for the*

Chronically Mentally Ill (1980), and the *National Plan of Research to Improve Services* (1991), focusing on people with serious mental disorders, were all developed through stakeholder participation, involving many of the same actors as the CSP process. Although neither the *Systems Act* nor the *National Plan for the Chronically Mentally Ill* was fully implemented, due to a policy shift under the Reagan administration, both had a considerable impact on the field (Koyanagi and Goldman, 1991). The *State Comprehensive Mental Health Planning Act* of 1986 (P.L. 99-660) and federal guidelines for implementation (NIMH, 1987) also bear the strong imprint of CSP philosophy. In part, this can be attributed to support from stakeholders who participated in developing the ideas and then carried them forward. Through the network, national leadership has emerged from each stakeholder group. Shared understandings have developed across boundaries and sectors, effective action has been taken and an ethos and culture of creativity and collaboration has emerged.

Harnessing research and evaluation

Having clarified what needed to happen and launched a strategy intended to make it happen, NIMH wanted to learn more about what actually was happening at each level. This led to an emphasis on learning from experience, not only through soliciting stakeholder feedback, but also through using more traditional forms of research, evaluation and programme analysis.

This reflected the desire of CSP managers to avoid becoming what Campbell (1976) had referred to as:

> *trapped administrators (who) have so committed themselves in advance to the efficacy of the reform that they cannot afford honest evaluation* (quoted in Turner and TenHoor, 1978, p.341).

Instead, they saw themselves as:

> *experimental administrators, justifying the reform on the basis of the importance of the problem, and not the certainty of the answer* (Turner and TenHoor, 1978, p.341).

There were numerous difficulties in evaluating a broad-based initiative which was also being impacted upon by forces beyond its control. Nonetheless, the CSP initiative has been extensively evaluated – so much so, that one observer has suggested that 'expenditures to study the programme must not fall all that far short of the money used to fund it' (Scull, 1990, p. 310).

That is, of course, an overstatement. But during 1978, CSP managers worked closely with NIMH researchers to design a multifaceted analysis and evaluation strategy. The list below illustrates the range of CSP related projects that emerged. These fall into the following slightly overlapping categories:

- nationally-managed *systems change studies,* focusing on methodology development and short-term evaluation (Stroul *et al.,* 1980; Tessler and Goldman, 1982; Stroul *et al.,* 1985);
- nationally-managed *client studies* focusing on demographic and clinical characteristics, service use, and quality of life of clients in CSS demonstration areas (Tessler and Goldman, 1982; Mulkern *et al.,* 1986; Mulkern and Manderscheid, 1989);
- *studies of local CSSs* to examine different organisational approaches (Grusky *et al.,* 1985; Grusky and Tierney, 1989);
- studies to develop *CSS needs assessment methods* (Ashbaugh *et al.,* 1982);
- *state evaluation projects* done as part of a CSP project (see, for example, Field and Yegge, 1982; Hammaker, 1983);
- numerous studies of local CSS innovations (see review by Anthony and Blanch, 1989).

Central to the whole evaluation strategy for CSP was an *'evaluability assessment',* followed by a 'short-term evaluation'. The aim was to analyse CSP's logic, examine the plausibility of the assumptions on which it was based, and develop an 'impact model'. The evaluability assessment led to a decision that the programme logic and intent were clearly enough defined to permit meaningful evaluation. *'Performance indicators'* were then developed and field tested to measure state level system change and local CSS development.

These studies found that CSP objectives were clearly understood and the intended activities were underway at each level – outcomes beyond what had been expected. This may have reflected the extensive use of leverage through performance contracting, supplemented by site visits and interactions at stakeholder conferences.

Objective evidence that the initiative was operating as intended was useful. In addition, CSP managers and other participants benefited from the process of conducting the project. This involved independent evaluators interviewing managers at all levels to clarify their 'if-then assumptions' about the causal links between programme activities and the ultimate goal of improving the quality of life. This process identified a need to clarify certain aspects of CSP and wider NIMH policy. It also raised a major question about whether programme goals were too ambitious for the extremely modest resources available (Tessler and Goldman, 1982).

The evaluability assessment methods and approach have potential relevance for other systems change efforts. Too often, reformers are unclear about what they want to achieve, and how

7

COMMUNITY SUPPORT SYSTEMS IN PRACTICE: EVALUATION EXAMPLES

Multi-site client studies, 1980-84

More than 1,000 randomly selected clients were studied in 1980 in fourteen varied CSS sites, and a similar number were studied in 1984 – using a 'uniform client data instrument' completed by case managers (Mulkern *et al.*, 1986; Mulkern and Manderscheid, 1989). In addition, the 1984 study collected follow-up data, as well as quality of life information on 600 clients being served in six 'exemplary' sites – two urban, two rural, and two suburban. Some of the main findings from these studies include the following:

- **local CSSs were indeed serving the intended population, both in 1980 and 1984, and were offering a wide range of CSS services;**
- **minority participation was proportional to the number in the general population;**
- **clients enrolled in CSSs 'appeared to have a reasonably good quality of life', although concerns remained about money, friends, and work in particular;**
- **participation in a CSS was associated with a reduced use of psychiatric hospitals, with rehospitalisation rates 25 per cent lower than those reported in the literature;**
- **numbers of clients enrolled in CSSs operating at least to some extent in accord with NIMH guidelines greatly increased from 1980 to 1984;**
- **by 1984, there were 352 districts in 20 'pilot states' attempting to provide a CSS;**
- **within the twenty pilot states, it was estimated that 350,000 clients were enrolled in new or modified programmes directly stimulated by CSP projects.**

Investigators concluded that CSP had 'clearly taken root in the original pilot states' and that 'with a few exceptions, CSP appears to have had considerable impact and to be operating as intended' (Mulkern and Manderscheid, 1989).

Organisational studies at local levels

To clarify how a CSS works locally under different circumstances, a descriptive organisational study was done of four CSS sites, each with a different way of providing essential CSS components:

- **a 'linkage model' in Alabama, in which the core agency focused on co-ordinating services provided by other agencies;**
- **a 'CMHC monopoly model' in Maine, where the core agency provided nearly all of the direct services and had control over both hospital and community resources;**
- **a 'social services-led model' in a Minnesota county with few psychiatric resources;**
- **a 'state hospital-led model' in New York, where a relatively new state facility served as the local CMHC, the CSS core agency, and the state psychiatric hospital (Grusky *et al.*, 1985).**

The study illustrated how the CSS 'accountability model' had been adapted to local conditions, and highlighted strengths and weaknesses of different approaches. For example, Alabama's co-ordination model had limited influence on the more powerful agencies whose resources were essential to CSS development. The social services-led model tended to reject difficult clients and served a predominantly female clientele. The other two models were somewhat closer to NIMH intent, because core agencies were managing and/or influencing more of the total resources required (Grusky *et al.*, 1985).

their interventions relate to a wider context. An evaluability assessment can clarify outcome criteria, identify gaps in logic, pinpoint unfounded assumptions or conflicting objectives being pursued at various levels, and provide opportunities for management or policy adjustments.

CSP managers also wanted to know whether local CSSs were serving the intended clients, what range of services were being offered and used, and how this related to the goal of improving the quality of life. Another concern was to understand how the CSS concept could be implemented under various local circumstances. Methods for answering such questions were tested in varied CSS sites through a series of collaborative projects, using a descriptive approach while the initiative was in a formative stage (see Box 7).

The evaluability assessment and the multi-site client studies were useful in obtaining continued NIMH and Congressional support for the CSP initiative. Equally important, however, they raised issues that enabled CSP managers to make timely refinements in programme policy and strategy. For example, although CSP managers were not in a position to garner additional resources to address shortfalls identified by the evaluability assessment, they were able to draft new programme guidelines to incorporate insights from the study.

The multi-site client studies produced important information on the quality of life of CSS clients. Despite encouraging aspects of the findings, many clients said they were lonely, most had money problems, and only 25 per cent were employed. These findings and discussions with stakeholders led to a growing emphasis within the CSP network on advocacy concerning income support. In addition, a new emphasis emerged on 'peer support', which has since been recognised as an essential CSS component.

Since the early 1980s, many state and local agencies have been directing resources toward consumer-initiated, consumer-run activities. In addition, some projects are hiring clients as mental health and community care workers. This shows how, in some instances, needs can be transformed into resources, and 'consumers' into 'prosumers' (Toffler, 1980) who themselves provide some of the help needed by others, while receiving support from their peers.

Another tool in identifying CSP lessons was programme analysis – somewhat less formal and costly than evaluation and research projects, but nonetheless very useful. For example, Beth Stroul (1982) was commissioned to analyse the systems change process as reflected in reports from pilot states and other documents. She found that most states used a combination of 'top down', 'bottom up' and 'lateral' approaches. Most states also gave considerable emphasis to developing a constituency to advocate for the CSP population. The strategies listed below were identified by the pilot states as particularly useful in service development:

- training conferences and workshops with follow-up technical assistance;
- altering state funding patterns to give CSS concepts and services priority;
- providing start-up money for statewide development of priority CSS components, such as housing;
- public education campaigns;
- developing one or more demonstration CSSs at local levels (Stroul, 1982).

The analysis and evaluation strategy and outcomes for the pilot programme have been fully described by Richard Tessler and Howard Goldman (1982), and briefly summarised and updated in a wider review by Beth Stroul (1984). Many ideas about the change process examined in these studies are relevant to national, regional or local development work in any country.

In addition to evaluation and analysis, NIMH has supported a large body of more formal research relevant to the CSS concept in practice. For example, Test and Stein (1978), Dellario and Anthony (1981), Braun *et al.* (1982), Kiesler (1982), and Anthony and Blanch (1989) have reviewed a range of research projects relevant to CSS issues.

In general, the various analysis, evaluation and research projects, including those carried out by state mental health authorities, have substantiated the value of CSS/CSP approaches. A number of the studies have contributed significantly to programme effectiveness, and the links between research and practice through the stakeholder network have had particular value. However, definitional and methodological problems have limited the generalisability of some of the studies (Bachrach, 1982a). For example, NIMH's intended distinctions between community systems, components and programmes have been overlooked in much of the research to date, making findings about effects of participation in 'a CSS' more difficult to interpret.

Despite this, Anthony and Blanch (1989) have concluded, after a detailed analysis of CSS-related research, that effective ways of providing particular components for particular groups of the CSP population have been well documented, and:

> *the need for CSS component services now has a base in empiricism as well as logic... A significant number of quasi-experimental and small scale experimental studies have been carried out... The stage is now set for large-scale, long-term, experimental studies of measurable replicable CSS-type interventions* (p.72).

Comparability of future studies could be enhanced – perhaps in collaboration with other countries – by building on and refining terminology and research methods developed during the pilot phase of CSP.

The CSP contribution: fig leaf or major reform?

Writing in 1985, one observer has summed up the CSP contribution like this:

> *As a fig leaf for the failures of public policy, the Community Support Programme is so tiny as to leave the obscenity of our current circumstances in full view* (Scull, 1985, p.310).

Other observers, however, point to substantial evidence that CSP has 'radically altered the perspective through which ... mental health services are viewed'. And this despite the fact that it constitutes only about $25 million in a federal mental health budget of over $900 million. According to this view:

> *... somehow CSP has played a leading (some might say dominant) role in reordering mental health priorities and redefining mental health services over the past fifteen years* (Scallett, 1992, p.2).

It is certainly true that funds for the programme have remained tiny in proportion to the scale and significance of the concerns it is meant to address. And in a wealthy and civilised society, the gap between current circumstances and CSP ideals is deeply troubling. The nature of the gap and some of the causes are discussed in turn below.

The 'long journey home'

CSP has had its greatest successes with the older 'deinstitutionalised' population. But evidence of remaining service inadequacies can be seen in the substantial numbers of people with serious and disabling mental illnesses who remain unreached by effective community-based treatment or support. It was estimated in 1990 that in the US there were somewhere between 150,000 to 300,000 people with serious mental illnesses living in public shelters and on the streets (Torrey *et al.*, 1990). Of those among the homeless who have a mental illness, about half also have an alcohol or substance abuse problem (Tessler and Dennis, 1989). Many of these are young adults whose behaviour often challenges service providers (Bachrach, 1982b). Resisting diagnostic labels and traditional services, they are particularly vulnerable – both to becoming homeless and to landing in jail.

There are an estimated 100,000 people with serious mental illness in US prisons and jails (Torrey *et al.*, 1990; Jemelka *et al.*, 1989). Another matter of concern is the plight of some people in locked nursing homes (Warner, 1985). In addition, there are still thousands of people living 'in the community' without adequate support. These include adults living with their parents, who have nowhere to go, no meaningful role, and little hope of recovery or rehabilitation.

Forces that help or hinder

Opportunities and services nationwide for the CSP population reflect the combined effects of numerous influences – both positive and negative – quite beyond a small government programme. Wider positive forces for CSP goals include progressive leadership by many state mental health authorities, progress in rehabilitation research, a national climate of support for self-help, and strengthened consumer and family advocacy at all levels. Major hindrances include negative professional and public attitudes, out-dated professional training, resource shortfalls, and funding policies that work against CSP goals (Parrish, 1989).

One fundamental and pervasive problem is the fact that both professionals and the public often view 'the CSP population' as 'hopeless cases'. Most professional training programmes in the US remain geared primarily to hospital or office-based services, cultivating neither the attitudes nor the skills for community support and rehabilitation.

Public attitudes are often characterised by the 'NIMBY' approach (Not in my backyard!). When difficulties arise 'in the community', the temptation is to try to get 'the problem' out of sight and out of mind. The visibility of mentally ill people among the homeless has led in some places to public pressure to rely more on hospitalisation (see Elpers, 1987 and Pepper, 1987 for discussion).

Despite these difficulties, evidence continues to accumulate that rehabilitation and social support approaches are effective in increasing coping ability, reducing symptoms, and improving the quality of life (Dion and Anthony, 1987; Anthony and Blanch, 1989; Gartner and Riessman, 1982). Even people with serious diagnoses and long-term problems can and often do recover, when given the right treatment, rehabilitation and support (Strauss *et al.*, 1985; Harding *et al.*, 1984).

Attitudes will change gradually as effective services become available on a wider scale. This requires the stakeholders in 'the mental health family' to work together – creating better services, generating credible data to show cost-effectiveness, and educating legislators and the public.

More frequently cited than attitudes as a hindrance to CSP goals are a cluster of funding problems. Goldman and Morrisey (1985) have highlighted challenges from wider socio-economic problems and increasing homelessness, saying that:

> *the community support activists may have found the balance between specialised mental health care and basic social welfare needs of chronic patients. They have learned the importance of caring as well as curing. But their reform is frail and in danger of failing, due to resource limitations ...and exaggerated expectations* (p.730).

Since the 1980s, a recession and reductions in federal, state and local mental health, housing and social health programmes have greatly impeded progress toward CSP goals. Indeed, US public housing and income support policies of the 1980s were disastrous for the poor (Lazare *et al.*, 1991). Campaigning by mental health stakeholder groups has helped secure changes in some policies, but not enough to compensate for reductions in affordable housing.

Some argue that the total funding available for treatment, housing and support for 'the CSP population' is simply not enough. An estimated $15.7 billions are spent in the US each year on services and supports for people with serious mental illness (Sharfstein, 1988). However, it has been estimated that this amount is sufficient to provide comprehensive mental health and community support services for only 44 per cent of those the CSP initiative is concerned with (Parrish, 1989). Others are more optimistic about managing with the total resources now available. David Mechanic (1986) has suggested that:

> *(although existing mental health funding) is not ample,.. when aggregated from varying funding sources and appropriately allocated, it provides a minimally adequate basis for organising more coherent services for the chronic mentally ill* (p.896).

Problems in allocating existing resources are widely acknowledged, however. Mental hospital budgets still consume on average two thirds of state mental health budgets nationwide (Aviram, 1990), but there is considerable variation from one state to another. Progress in resource transfer has been limited. Medicaid and insurance funding remain largely tied to medically oriented approaches, (Talbott and Sharfstein, 1986; Vischi and Stockdill, 1989), although there have been incremental improvements since the early 1980s (Koyanagi and Goldman, 1991). In addition, US funding patterns remain fragmented and extremely complex. A patchwork of overlapping and conflicting reimbursement mechanisms, eligibility requirements and grant or contract programmes requires service managers to devote enormous effort to marshalling resources from various sources – a task made more difficult in a time of budget cuts. The diversity offers many options, and the competition sometimes stimulates creativity. But it often works against creating service systems and encourages short-term projects instead.

Serious structural problems also impede CSS development, particularly in the cities. Efforts to tackle these have increased in recent years. These include 'capitation' schemes (Mechanic and Aiken, 1989), and a major private foundation initiative – the Robert Wood Johnson Foundation Demonstration Programme on Chronic Mental Illness – based in part on CSP concepts (Goldman *et al.*, 1992).

As states and cities make structural and financing changes in the right direction, some are establishing 'local mental health authorities', with unified fiscal control over hospital and community mental health budgets. This creates an incentive to use hospital savings to improve community services (Stein, 1989; Stein *et al.*, 1990).

Despite these encouraging signs, a lack of alignment between the CSP vision and 'mainstream' national policies affecting funding for income support, housing, health and social services remains the major hindrance to developing community support systems nationwide.

The CSP contribution

In some instances, the CSP initiative has served the function of 'damage limitation' in the face of budget cuts, housing shortages, and other problems outside the control of mental health leaders. Beyond this, various observers have highlighted the catalytic role of CSP, pointing to numerous achievements.

The CSP philosophy has become widely accepted; all 50 states have participated in the programme for several years; and 'the CSP population' has become the main priority for public mental health programmes. During the pilot phase, CSP succeeded in 'leveraging' an estimated $18 of state, local or other funding for each federal dollar spent (Jaskulski and Robinson, 1990). About half the states have passed legislation to pursue CSP goals. National legislation, too, now reflects the CSP approach in the State Comprehensive Mental Health Planning Act of 1986 (P.L. 96-660) and the guidelines for implementation (NIMH, 1987). In this respect, CSP is gradually being 'mainstreamed' into US mental health policy.

Sound approaches to providing local community support systems are now well developed and are being implemented under a variety of conditions. Community support systems in practice have been described by Warner (1985), Fleming and York (1989), Mosher and Burti (1989), Stein (1990) and others. CSS 'components' such as crisis stabilisation programmes, Fountain House-type services, supported housing and work, case management, work with families, consumer-run alternatives, mutual and self-help groups and other such services have spread rapidly in recent years (Stroul, 1986). Indeed, the number of agencies providing a Fountain House type programme (known in the US as 'psychosocial rehabilitation programme') has increased from about a dozen in the early 1970s to some 1,500 today (IAPSRS, 1990).

By 1984, it was estimated that more than 350,000 clients were participating in local 'CSSs' in the 20 pilot states (Mulkern and Manderscheid, 1989). Thirty additional states have since joined in the federal initiative and completed their five-year strategy development and implementation cycle; therefore, the numbers of people enrolled in something approaching a 'CSS' would have more than doubled since then.

Of course, definitional problems make it difficult to interpret statements about numbers of people enrolled in CSSs. In some cases, names of services and settings have been changed, with little real change in substance. And only a few localities have succeeded in creating complete community support systems in the sense intended by NIMH. Nonetheless, there is no doubt that the initiative has helped thousands of people with serious diagnostic labels and extensive hospitalisation histories to manage their difficulties, live in better conditions, make new friends and improve their self-esteem.

In many ways, the programme has acted as a catalyst over the past fifteen years for a reform 'movement' that was quietly trying to happen but needed encouragement from the top. As seen from the standpoint of two 'primary consumers' and a family member:

> *The NIMH Community Support Program is managed by a small branch in the enormous scheme of federal government. It has not brought about the significant changes in programs and advocacy for*

> *people with mental illness because of 'a directive' but by 'an invitation'.*
>
> *Consumers, families, and professionals all have been invited to help draw a map and to travel the road together. The map or guide is the CSS concept ...*
>
> *The success in getting so many diverse groups and personalities to buy into and advocate for CSSs has been nothing less than miraculous. It has come about as a result of this primary concern for the individual and an attitude of attentive listening that pervades community support philosophy* (Chamberlin *et al.*, 1989, pp.105-106).

A study of CSP by the Rand Corporation (Glennan *et al.*, 1986) attributes such achievements to 'good timing, organisational backing, the use of a participatory planning process, support in the field, a flexible concept, and willingness to make adjustments'. Other ingredients include CSP's clarity about what needed to happen; its development of a shared vision and a flexible concept based on genuine stakeholder involvement; its systems approach; and its ability to orchestrate a wide range of activities toward a single goal – improving the quality of life of the population of concern.

But perhaps the most powerful ingredient in what has been achieved and the key to future achievements is the commitment to work across ideological, sectoral and other boundaries – listening and seeking to learn from the insights of service users, families and colleagues with differing perspectives. Sharing of experience through the network is building a spirit of determination to overcome all obstacles – bureaucratic difficulties, disadvantage, discrimination, mental illness itself – a spirit also present in Britain. Meeting the challenges of the 1990s on both sides of the Atlantic will depend on sustaining and kindling that spirit.

Critical issues for Britain

3

> *Just as it is necessary for individuals to accept and even welcome challenges to their maps of reality and [ways of operating] if they are to grow ..., so it is also necessary for organisations to accept and welcome challenges if they are to be viable and progressive ...*
>
> *... one of the most exciting and essential tasks facing our society in the next few decades is to build into the ... structure of our organisations an* institutionalised openness *and* responsiveness to challenge *which will replace the institutionalised resistance currently typical* (Scott Peck, 1978, p.55.)

As in the United States, Britain's mental health services are changing. The momentum for change is powerful, stemming from three major sources: continuing government commitment to a policy of hospital closures; major restructuring of health and social services as a result of the NHS and Community Care Act 1990; and growing pressures from users, carers and the public for more responsive services. In theory, outmoded systems of care are gradually being transformed, providing more choice for service users and families and better value for money. In practice, it is not always clear whether services are improving or not.

The current situation

What *is* clear is that the patchy and uneven development of community services remains a matter of widespread concern (Quaker Social Responsibility and Education, 1989; Sayce, 1991b). There is also concern about the manner in which hospital closures are being planned and community services developed – often without adequate consultation with mental health workers, service users and families (Ramon, 1992).

Many service improvements and innovations have been developed (Echlin, 1988; Marks and Scott, 1990), and a few districts have succeeded in establishing a wide range of services with only limited reliance on psychiatric hospitalisation (Jenkins, 1991). But wide variations remain between districts and localities in services on offer and per capita spending on mental health (Audit Commission, 1986; Murphy, 1991). In most districts, important service elements are missing. Nor can most districts offer real choice to service users (Sayce, 1991b). One member of Parliament has summed up the situation like this:

> *I have visited hospitals and social services the length and breadth of the UK and with the exception of a few bright spots, community care simply is not working (Winterton, quoted in Quaker Social Responsibility and Education* (QSRE), 1989, p.11).

Responsiveness and sensitivity of services are also at issue. It is well documented that certain ethnic minorities are more likely than others to be hospitalised compulsorily, and given drugs and ECT rather than counselling (Fernando, 1988). Among the wider population, a survey of experience of over 500 people receiving mental health services in England and Wales concluded:

> *the picture that emerges is a mental health system geared to create career patients rather than one which enables people to lead active lives as valued members of their communities* (MIND/ Roehampton Institute, 1990, p.1).

The burgeoning 'user movement' in mental health is generating greater awareness of these issues (Barker and Peck, 1988; Rogers and Pilgrim, 1991). A growing emphasis on 'user involvement' offers fresh impetus toward planned, principled change. At national level and in some districts, a dynamic partnership is developing among managers, professionals and user groups. A shared aim is to make services more sensitive and responsive, while expanding opportunities in the wider society.

That there are grounds for concern about service development, however, has been widely acknowledged for some time. In 1986, the Audit Commission's influential report on community care concluded:

> *Progress ... has been slow and uneven across the country, and the near-term prospects are not promising*
>
> *... the progress being made ... can usually be attributed to individuals with enough determination to manoeuvre their way around the system ... succeeding in spite of, not because of, the present organisational and financing arrangements*
>
> *Fundamental underlying problems need to be tackled ... and radical steps will be necessary ...* (p. 76).

Since that report was issued, a series of major policy reviews and white papers (Griffiths, 1988;

Cm. 555, 1989; Cm. 849, 1989) have attempted to devise solutions to service difficulties. In 1990, bold decisions were taken: the 'internal market', NHS trusts and GP fundholding were implemented; lead responsibility for community care was given to local authorities; and from April 1993, changes in residential care funding were introduced. Additional decisions include the Mental Illness Specific Grant, the 'Care Programme Approach', and capital loans for bridging finance. Also important was the decision to 'ring-fence' community care funding for all priority population groups, while leaving the Mental Illness Specific Grant intact.

By 1992, the Audit Commission observed that recent policy decisions have stimulated 'an ever increasing cascade of change', and 'it is not yet possible to describe the full implications'. There is no doubt that coping with so much change at once presents major challenges for managers, professionals, private and voluntary organisations, consumers and community members. In the process, agency and professional roles become unclear, philosophies and priorities conflict, people become demoralised, and it becomes more difficult than ever to get resources into the right place at the right time.

In many cases, for those directly involved, the day to day aim is sheer survival. Managers and professionals struggle to defend programmes (and often their jobs) from restructuring and budget cuts (Hatchett, 1992); families struggle to cope without adequate information, respite care, guidance or support (NSF, 1989). Many service users live impoverished lives in the community with inadequate incomes, few friends, no meaningful social roles, and an unsatisfactory quality of life (Barham and Hayward, 1991).

In addition, 'there is some evidence to support the theory that many mentally ill people end up in prison, on the streets or in temporary hostels' (Office for Public Management, 1992). Finally, a number of tragic incidents of violent or self-destructive behaviour by people with psychiatric diagnoses have taken place over the past year, intensifying public concern, and highlighting weaknesses in available services.

In the new policy framework, responsibilities for coping with mental illness are shared among a wide range of organisations. There is greater reliance than ever on individuals, families, the voluntary and private sectors, and the wider community. This makes service planning and provision more complex than ever.

Recent policy changes have also raised new issues. How will mental health services fare in NHS trusts (Sayce, 1992)? How can the needed range of services be developed in the contract culture (Heginbotham, 1990; Common and Flynn, 1992)? How will residential funding changes affect living options for people with a mental illness (Blom-Cooper and Murphy, 1991)? What can be achieved through the mental health specific grant (Hogman and Westall, 1992)? And how can care or case management best be implemented (Beardshaw and Towell, 1990; Ryan *et al.*, 1991; Thornicroft, 1991)?

Meanwhile, fundamental problems under discussion for several years remain essentially unresolved. Successive reorganisations over the years have pushed mental health lower in both NHS and social services structures (Murphy, 1991), in many cases worsening its position as a 'poor relation'. Major NHS mental health resources remain locked in outmoded systems, and many fear that the increased responsibilities of social services departments have not been accompanied by adequate resources (Social Services Committee, 1990b). At the same time, some of the new local policy options threaten to fragment mental health planning and provision even further – through widely varying arrangements for NHS trusts, purchasing, care management and related functions. Indeed, some of these policy changes may have increased the risk that patchy, slow and uneven service development will continue.

The central challenge for the 1990s is to find ways, in the 'mixed economy of care' and within available resources, to ensure development in every district and locality of a coherent services network which is capable of responding to the needs of all sectors of the local population in a dependable, yet flexible way. This means using the new policies creatively: managing change through a process that empowers both clients and service workers, creating system coherence in the midst of complexity, and avoiding the policies becoming ends in themselves.

Six critical issues

This section examines six fundamental issues in managing the process of change in a British context, drawing on relevant aspects of US experience.

1. How clear and comprehensive are the vision, philosophy and goals concerning what needs to happen?
2. How satisfactory are the current ways of involving stakeholders – especially service users, carers, and professionals – in shaping and refining goals, concepts, and strategies?
3. What can be done to encourage a systems approach in every district? Is there a need for a unifying concept to integrate planning and action at local levels?

4 What can be done to clarify and strengthen national, regional, and local leadership for continuous, planned, principled change?

5 How can budget-holding and other funding policies and incentives be improved to support service goals?

6 What structures and processes are needed at each level to encourage experiential learning to improve policy and practice?

1 A vision of what needs to happen

Essential to achieving positive change in a changing environment is a widely shared vision of what needs to happen. The aims of the whole enterprise must be clear to, and fully supported by, those responsible for carrying it out, and there must be some measure of agreement over what matters most. According to Elaine Murphy:

> *In the twentieth century we have abandoned the old vision, having recognised its limitations, but we have created no new vision to replace it. We must now develop a vision of community mental health care which can provide inspiration for everyone concerned with mental disorder and which will serve to drive political action to turn vision into reality* (Murphy, 1991, p. 6).

Too often, service managers and providers work at cross-purposes or in an unco-ordinated way, with unsatisfactory results for clients and families – in part because of differences in philosophy and beliefs about underlying purposes. Such problems can be reduced by constant dialogue across boundaries to clarify the vision and keep it in focus.

Service organisations often try to do this through their mission statements or values statements. In Britain, such statements have recently been identified as among eleven 'key aspects of organisational fitness' for organisations in the mental health field. Too often in Britain, however, such statements are only paper exercises, seldom used or referred to – in contrast to the greater importance often attached to such statements in the US (McAusland and Wistow, 1992).

In mental health, the language expressing vision, values, mission or goals has particular significance, indicating how planners perceive service recipients. Service users on both sides of the Atlantic have pointed out the damaging effects of 'mentalism' – negative, crippling stereotypes about the people the system is intending to help (Chamberlin, 1988; Pembroke, 1991). Every word in mission statements must be chosen with care, to reflect as sensitively as possible what matters most.

The government's vision

This section examines the government's 'vision' for mental health policy and identifies issues requiring further thought and discussion.

8

VISION STATEMENTS: THE HEALTH OF THE NATION (1991; 1992)

Objective initially proposed:

> **To reduce the level of disability caused by mental illness by improving significantly the treatment and care of mentally disordered people (1991).**

Objective as revised in white paper:

> **To reduce ill-health and death caused by mental illness ... (through):**
>
> **an appropriate balance of prevention, treatment and rehabilitation;**
>
> **the development of services and practice in both primary and secondary care;**
>
> **action outside the health and social services (1992).**

Target initially proposed:

> **A single measurable target over the next decade would be to realign the resources currently spent on specialist psychiatric services into district-based services, thereby allowing many of the remaining 90 large psychiatric hospitals – relics of an outmoded pattern of care – to be closed before 2000' (1991).**

Targets as revised in white paper:

> **to improve significantly the health and social functioning of mentally ill people;**
>
> **to reduce the overall suicide rate by at least 15 per cent by the year 2000 (from 11.1 per 100,000 population in 1990 to no more than 9.4);**
>
> **to reduce the suicide rate of severely mentally ill people by at least 33 per cent by the year 2000 (from the estimate of 15 per cent in 1990 to no more than 10 per cent).**

Quoted from Cm. 1523 (1991) and Cm. 1986 (1992), *The Health of the Nation: A Strategy for England*, HMSO, London.

The most authoritative official vision statements concerning mental health in Britain are found in *Better Services for the Mentally Ill* (Cmnd. 6233); *Caring for People* (Cm. 849); and, more recently in *The Health of the Nation* first in a green paper (Cm. 1523) and then a white paper (Cm. 1986) – See Box 8. The green and white papers outline a health strategy for England, and identify mental health as one of five 'key areas'. The white paper promises an ongoing process of further strategy development and refinement, thereby providing a framework for an important national dialogue.

Changes in focus between the green and white papers demonstrate government efforts to

9

ISSUES CONCERNING OBJECTIVES AND TARGETS FOR ENGLAND'S MENTAL HEALTH STRATEGY

- **Should the strategy remain focused only on providing services for people with a mental illness, or should it also include developing opportunities?**
- **What constitutes an 'appropriate balance between treatment, rehabilitation and prevention'? And how is prevention to be reflected in the strategy?**
- **What are the specific improvements needed in primary and secondary care to reach the targets?**
- **Which are the 'priorities for action outside the health and social services sectors'? And where do improvements in housing and employment fit?**
- **What activities could be developed at primary care level, in the workplace, at schools, and elsewhere to empower people to maintain or resume responsibility for their own mental health?**

take certain stakeholder views into account. For example, the Royal College of Psychiatrists (1991), the Royal College of Nursing (1991) and others objected to the green paper emphasis on closing hospitals as 'the single target'; in the white paper, the target was reformulated. This illustrates the importance of distinguishing between intermediate objectives and ultimate objectives. US experience has shown that community mental health resources can be increased and use of mental hospitals can be reduced without necessarily reducing disabilities or enhancing the lives of the traditional clientele of mental hospitals. Hospital closures and an increase in community mental health resources should be seen as means towards an end, not as ends in themselves.

In a long-term strategy, the precise wording of such objectives can have a major impact on how energies and resources are expended. If objectives are too broad, poorly focused efforts may neglect pressing needs – a frequent allegation about the CMHC movement in the US. On the other hand, if objectives are too limited, important opportunities may be lost. For example, some comments on the green paper cautioned against focusing only on the treatment system or on people already disabled (MIND, 1991; Institute of Health Services Management, 1991a).

The success of England's mental health strategy will depend in some measure on how well it distils and balances the views of the main stakeholder groups – including users and carers – about what matters most. This means that the strategy must be expressed in terms that will stimulate well-considered action at all levels. Some questions that deserve further discussion concerning objectives and targets are identified in Box 9.

As the strategy evolves, individual, family, community, professional and government assumptions about roles in maintaining mental health and coping with mental illness also deserve examination. A World Health Organisation publication raises one such issue:

> *Too often an effective primary health care system is seen as a more efficient, humane and effective 'delivery' system; it delivers a commodity, namely health, which should in fact be within the ability of people to obtain for themselves.*
>
> *Health should, as far as possible, never be 'given to' or 'provided for' people. On the contrary, people should be helped to be constantly and actively involved in securing and promoting their own health* (WHO, 1990, pp.7-8).

In developing the strategy, ways must be sought to empower people to maintain or assume greater responsibility for their own mental health – preventing a downward spiral of dependence on medication, stigmatisation, segregation, and debilitation.

England's primary care system is a vital resource for community-based mental health care. General practitioners are the first contact for most who seek help for mental health problems, acting as gatekeepers to specialist services (Goldberg, 1991). At present, however, many hard-pressed GPs have little to offer for such conditions aside from a few minutes of friendly concern, medication, and in some cases referral to a psychiatrist. As a result, people may become dependent on prescribed tranquillisers (Petursson and Lader, 1981), instead of developing the insight, skills or support to cope with their difficulties in a healthier way. Nonetheless, a survey of 500 people with mental health problems indicated that seventy-four per cent found their GP 'helpful' or 'very helpful' in dealing with their problems (MIND / Roehampton Institute, 1990). Recognising both the strengths and limits of primary care in mental health, MIND has suggested the following national objective:

> *to create access through every GP surgery to a range of options for people in mental distress. Counselling should be available and, at a minimum, comprehensive information held on other alternatives such as self-help groups, psychotherapy and complementary therapies* (MIND, 1991, p.7).

Some initiatives are developing within primary care to strengthen self-reliance and build links with community resources (Newton, 1992; GPMH, 1989). These deserve further attention and expansion in the context of the mental health strategy.

A largely untapped resource in strategies to cultivate healthy self-reliance are mutual and self-help groups – 'people who feel they have a common problem and have joined together to do something about it' (Richardson and Goodman, 1983). Certain well-defined approaches have demonstrated their value with mental illness and distress (Rappaport *et al.*, 1985; Turner-Crowson and Jablenksy, 1985). The US and some European governments promote such developments (Mental Health Policy Resource Centre, 1991b; Hatch and Kickbusch, 1983), and it has been suggested that:

> *the sooner self-help is fully taken into account as one of the basic components of primary health care, in developed and developing countries alike, the sooner we will achieve health for all* (Robinson, 1980).

England's wider health strategy stresses that 'everyone has a part to play in improving health', and highlights the importance of participation. It also advocates development of 'healthy alliances' – with schools, employers, and other community organisations. Applying these ideas to mental health requires more thought and discussion at all levels.

The question of community

In both US and British policy, the term 'community' is used in a wide variety of ways – often to denote any location *except* a mental hospital. People in general hospital psychiatric units, substandard nursing or boarding homes or even on the streets are sometimes referred to as being 'in the community'. Regrettably, reform efforts in mental health have often focused on shifting people from one setting to another, assuming that anything that happens outside the hospital is beneficial. There have also been simplistic assumptions that families and benign and caring communities will be able to provide what is needed by very disabled, disturbed or disturbing people previously cared for by the public sector. But experience has shown that the issues are far more complex and subtle than that.

It is time to shift discussion from *where* service delivery takes place to *what* should take place and how it can best be done in different circumstances. This must include consideration of how best to help people meet basic needs, develop problem solving skills and a sound philosophy of life, make friends, contribute to some enterprise, build self-esteem, and live, learn and work in environments of their choice (Anthony *et al.*, 1990). Equally important is ensuring adequate support to families of people with serious mental illness and where necessary to employers, law enforcement officials, neighbours and others.

Recent government documents recognise some of these concerns. See for example, the frequently quoted statements in Box 10, from *Caring for People.*

Ambiguities remain however about the concept of 'community' in British social policy (Walker, 1982; Bulmer, 1987). For example, are policy intentions to provide care in the community or by the community?

One perspective on the concept of community is to acknowledge that everyone needs a network of people from whom to receive and to whom to give support; these are our personal 'communities' – described by Caplan (1974) as 'personal support systems'. These continuing relationships, sometimes widely scattered geographically, play a vital role in helping people cope with inevitable stresses of life. It is well known that people with mental health problems often find it hard to create lasting reciprocal relationships; many come to rely on professionals and medication as partial

10

PHILOSOPHY OF 'COMMUNITY CARE' FROM CARING FOR PEOPLE (1989)

The government's approach to community care focuses on:

- **enabling people to live as normal a life as possible in their own homes or in a homely environment in the local community;**
- **providing the right amount of care and support to help people achieve maximum possible independence and, by acquiring or re-acquiring basic living skills, help them to achieve their full potential;**
- **giving people a greater individual say in how they live and the services needed to help them to do so;**
- **promoting choice and independence and allowing a range of options;**
- **providing help and support for carers;**
- **responding flexibly and sensitively to needs of individuals and their carers;**
- **providing services that intervene no more than is necessary to foster independence;**
- **providing services *that concentrate on those with the greatest needs* (emphasis added).**

Quoted from Cm. 849 (1989) *Caring for People: Community Care in the Next Decade and Beyond,* HMSO.

11

'MODEL PROGRAMMES' PROVIDING COMMUNITY BUILDING AND SOCIAL SUPPORT

- **The *'Compeer model'* matches volunteer community workers with people recovering from emotional disorders and has spread from New York to other parts of the US (Skirboll and Pavelsky, 1984).**
- **The *'community worker model'*, developed in rural Wisconsin, employs 'ordinary, healthy people' part-time to befriend long-term mentally ill people (Cannady, 1982).**
- ***Consumer-run alternatives*, such as user-run drop-in centres, employment and housing projects pioneered by ex-patients in the 1970s, have been promoted and funded by NIMH since the mid 1980s (Chamberlin, 1988; Mowbray *et al.*, 1988; Mowbray and Tan, 1992).**
- **GROW, *a mutual-aid/self-help* organisation, works in partnership with statutory bodies, using a 12 step educational programme adapted by members. Originating in Australia 30 years ago, GROW has spread to the US, Ireland and six other countries, with a few informal groups in England. Extensive research has documented low operating costs and substantial benefits to participants (Rappaport *et al.*, 1985; Zimmerman *et al.*, 1991; Salem *et al.*, 1988).**
- **The *Chesterfield Community Centre* in the UK provides back-up support and places to meet for some 30 self-help groups for people with mental health problems (Milroy and Hennelly, 1989).**
- ***Family support and advocacy groups* such as the National Schizophrenia Fellowship and the US National Alliance for the Mentally Ill offer information and social support to families of people with psychiatric problems.**

substitutes. This raises a question: what can be done to enable people to build and sustain their own networks of friendship and mutual support?

Britain has pioneered the development of 'therapeutic communities' – first in hospitals, and later in ordinary houses. In most cases, these are intended as temporary; but some are intended to last indefinitely. The principles of the therapeutic community movement have influenced wider philosophies and practices in community care, reducing distance between staff and clients and helping clients take charge of their lives (Kennard, 1983; Terrington, 1985).

In the more usual sense of community, the voluntary sector and emerging consumer and mutual help organisations have much to offer. For example, mental health service user groups are spreading rapidly in Britain and have recently formed a National Advocacy Network. In the process of providing individual advocacy, public education and advice on mental health service planning (Beeforth *et al.*, 1990), local groups also provide meaningful roles for their members.

In some cases, professionals act as catalysts in encouraging people with common concerns to build personal support networks. The clubhouse (or 'psychosocial rehabilitation') approach now so popular throughout the US and recently established in a few places in England exemplifies this. Clubhouse activities are carefully designed to enable members to develop new skills and to feel and be needed and valued (Beard *et al.*, 1982). Box 11 identifies other 'model programmes' concerned with community building and social support. Some of these ideas have been widely adopted or adapted in various parts of the US.

A major challenge for the 1990s is to clarify philosophies and principles of 'community care' – listening to service users, families and professionals – and using the new policy framework to support people's needs for genuine community.

2 Involving stakeholders

A mental health report from the Institute of Health Services Management has emphasised the need for purchasers to 'have a vision' (IHSM, 1991b). This raises an interesting question: whose vision is it anyway? More specifically, whose is the guiding vision for a district or locality within which there are at least two major purchasers (health and social services) and two major manager/providers involved with mental health, with GP fundholders adding yet another dimension? Central government and regional health authority views will also shape 'the vision' – particularly if there is a timetable for hospital closure. Also to be considered are the views of service users, carers, minorities, professionals, voluntary groups and others – all with varying perspectives about what matters most.

Wistow and Webb (1985) have identified certain 'highly demanding' conditions for effective joint planning across health and social services boundaries including:

> *the existence of a systems-wide perception of needs and service interdependencies; a developed analytical capacity; consensus on the nature of need and the care paradigms for meeting it; and organisational and professional altruism – a willingness to surrender resources and authority in order to achieve a systems-wide objective* (Quoted in Audit Commission, 1986, p.60).

Implicit in such conditions is a shared vision. It is obvious, however, that with so many interests involved, such conditions do not generally develop of their own accord. Someone must take responsibility for creating them.

Consultation documents, surveys, and written responses can be useful in balancing stakeholder views. But there is no substitute for well-structured and continuing dialogue between managers, policy makers and stakeholder representatives. For this to succeed, special attention and creativity are needed:

> *not only in the design of the new services in the community, but equally in the design of the process of service development itself* (Kingsley and Towell, 1988, p.52).

In the CSP initiative, stakeholder representatives played a key role in shaping a guiding national vision, then helping to translate it into a planning concept and development strategy. Each stakeholder perspective was valued, and efforts were made to take all relevant views into account as far as possible including, of course, those of the 'experts'.

The importance of stakeholder involvement is increasingly recognised in Britain, both by national organisations and at local levels. Conferences and stakeholder consultations have been organised by the National Centre for Mental Health Services Development, the King's Fund, the Department of Health's Mental Health Task Force, Research and Development for Psychiatry, the NHS Training Directorate, MIND, COSHE, Good Practices in Mental Health (GPMH), the Nuffield Institute, the Mental Health Foundation and others. Events such as, for example, a conference on user involvement in Brighton (MIND, 1988) and a 'search conference' (MIND / COHSE, 1989) have expressed a strong spirit of collaboration. At present, however, there is no national forum that brings together balanced representation from all major stakeholder groups to examine emerging issues and plan joint action.

At local levels, the separation of purchasing from provision has brought an emphasis on consulting widely about service priorities. Social services departments are now required to develop community care plans, in collaboration with district health and family health services authorities. These offer opportunities for consulting stakeholders on service priorities. The need for stakeholder involvement, especially in hospital closures, has been elaborated by Ramon (1992), and various approaches are described by Towell, Kingsley and McAusland (1989).

Achieving authentic and balanced stakeholder input is a challenging task. It is not easy to avoid tokenism, or to ensure that the interests of diverse service users, carers, professionals, managers, policy makers and others are adequately represented. Integrating and balancing the range of views is another aspect of the challenge. Each group has a different knowledge base and mind set; at times, ideology and professional jargon can become barriers to fruitful communication (Hatfield, 1986; Pembroke, 1991).

Without sensitive preparation and committed follow up, convening stakeholders can be unproductive – even counterproductive – despite the best of intentions. Some conferences are too short to handle the complex issues at hand, or there may be no clear process for follow-up. Others have a one way structure, precluding real dialogue. Sometimes issues are inadequately defined, making practical outcomes impossible. There are also dangers of re-opening polarising debates or watering down the discussion to the least common denominator of understanding. And sometimes, participants may appear to be reaching agreement, but may have no real commitment to putting new ideas into practice.

Skilful conference designs, however, can help each group to learn from others, while sharing its own perspective. Interactive approaches are vital, and skilled facilitation may be needed to created an atmosphere that builds trust and co-operation, using 'win-win' approaches to the major issues (Fisher and Ury, 1992), focusing and re-focusing on issues of common concern. Often, the vision of key local stakeholders can be expanded by participating in regional or national events.

The Social Services Committee (1990a) has suggested that the success of community care will depend in large part on collaboration – amongst statutory agencies at the macro level, and different professionals at the micro level. Collaboration across stakeholder perspectives is equally vital. But how satisfactory are the current ways of involving stakeholders in the UK – especially service users, carers, managers and professionals – in shaping and refining goals, concepts and strategies?

3 A systems approach in every district

Another way of encouraging collaboration and system coherence is to develop a unifying concept or planning model that provides a systems perspective. This can help people see their roles as part of a larger whole. Such a concept is helpful, of course, only if well formulated and widely owned.

In the US, flaws in the CMHC concept and the exclusion of key stakeholders (notably state mental health authorities) from the process contributed to deficiencies in community mental health development. The CSS concept was developed at a national level to assist with local planning for a population particularly vulnerable to neglect. It defined the main ingredients of an emerging national vision in terms that could be adapted locally.

In Britain, service design concepts have relied for many years on *Better Services for the Mentally Ill* (Cmnd. 6233). But this dates from 1975 and no longer reflects the best thinking about what matters most. Recent policy documents (Cm. 849 and Cm. 1523) have reaffirmed the 'better services' approach. However, this approach has now been superceded by the *Health of the Nation Key Area Handbook on Mental Illness* (Department of Health, 1993).

The Handbook provides the clearest explanations to date of how needs assessment, stakeholder involvement, individual services planning, purchasing, providing, services monitoring and evaluation are intended to work together. It is addressed to health, social services and family health service officials, as well as to organisations in the voluntary sector, and it emphasises shared responsibilities. It also identifies a wide range of service settings likely to be needed at local levels. Thus, in many ways, it provides a much needed systems perspective.

It does not, however, offer clear guidelines about priority sub-groups within the larger population of people with mental health problems. Nor does it specify essential service functions. Indeed, many vital questions about service priorities, design and organisation are left to local decision. Such a flexible approach has obvious advantages. If, however, the intent is to overcome patchy and uneven service development, this approach has serious drawbacks, unless effective compensating strategies are adopted. Key issues are discussed below.

Priority populations within priority populations?

The first pre-requisite for effective local systems of services and support is clarity about the populations to be served. It is also vital to realise that those most in need may be least able or willing to seek help and the most vulnerable to the 'revolving door' syndrome – constantly being referred from place to place absorbing substantial resources but receiving little genuine help.

As noted earlier, need for mental health treatment or support cannot be equated with demand (Wing, 1991, citing Matthews, 1971). Sometimes service demand and use may increase, even when not strictly necessary, while people in need are neglected. This was illustrated in the US in the 1960s and 1970s, when access to, demand for and use of CMHC services increased dramatically, while the traditional clientele for publicly funded mental health care remained neglected.

The Health of the Nation (1992) calls for a focus on 'mentally ill people' and people at high risk of committing suicide – both among the general population and amongst people with severe mental illness. The parameters are greatly expanded, however, by including prevention and primary care as well – ideas further developed in *The Mental Illness Key Area Handbook* (1993). Yet *Caring for People* (1989) specifies that services should 'concentrate on those with the greatest needs'. All this raises critical issues about priorities within the larger 'priority population'.

British literature recognises that in every district there are a number of somewhat overlapping groups of current and potential service recipients with varied and changing needs. Groups frequently identified include:

- some 26 percent of the population, according to Goldberg (1991) who consult their doctors every year because of mental distress or mental illness, sometimes referred to as 'the new clientele' (Patmore and Weaver, 1991);
- the 'old long-stay population,' being resettled from hospital, many of whom are elderly (Leff, 1990; TAPS, 1990);
- the 'new long-stay / term population,' with disabling mental health problems (O'Driscoll *et al.*, 1990; Thornicroft *et al.*, 1992), now likely to spend increasing periods 'in the community', where they may have access to alcohol and street drugs and where they may not be perceived as ill or disabled;
- people considered 'difficult to place', often with 'challenging behaviour' (Coid, 1991; Dass *et al.*, 1991), including offenders with a mental disorder revolving in and out of the criminal justice and mental health systems (NACRO, 1992; Cm. 2088, 1992);
- homeless people with mental illness who would benefit from treatment and rehabilitation services as well as housing assistance (Fischer and Breakey, 1986);
- children and adolescents with severe emotional disturbances, including victims of neglect or abuse (Quinton and Rutter, 1984; Kutz, 1992; Williams and Skeldon, 1992);
- the large numbers of elderly people with mental health problems, including growing numbers who are over 85 (Audit Commission, 1986);
- people from black and other minorities amongst all the above groupings, for whom present services often miss the mark (Fernando, 1988).

Getting the balance right in serving such diverse populations in the community requires considerable clarity about the numbers, location, needs and preferences of various groups and sub-groups within each district.

US experience demonstrates the importance of clarity about such issues – particularly in a time of shrinking resources. Belated recognition of this was reflected in the Mental Health Systems Act of

1980, which called for a national priority to meet the needs of the chronically mentally ill (NIMH, 1980), and focused attention on other groups likely to be 'unserved, underserved, or inappropriately served'. These ideas retained influence for some time, despite repeal of the Act itself. But just as the US picture improved to some extent in work with former long-term mental hospital residents, a new population emerged, sometimes unfortunately referred to as 'young adult chronic patients' (Bachrach, 1982b) with even more complex and challenging needs.

There is some evidence that CMHCs in Britain are serving a new clientele, to the neglect of the traditional clientele with more severe difficulties (Patmore and Weaver, 1991). In contrast, some argue that many health authorities are focusing on resettlement of 'old long-stay' patients, to the neglect of 'new long-stay' or 'long-term' (Dass *et al.*, 1991).

From the late 1970s, NIMH sought to address such concerns by encouraging states to develop clear service criteria and priorities based on an understanding of the unique characteristics, preferences and concerns of various groups at risk. For example, 'chronic mental illness' has been defined by NIMH and most states based on a combination of criteria including disability, diagnosis and duration (Schinnar *et al.*, 1990).

One US 'psychiatric survivor' has observed, however:

> *it should not always be necessary to show your schizophrenia card to get help* (Unzicker, 1990).

It is true that well-intended and necessary eligibility criteria often risk stigmatising people, acting as self-fulfilling prophecies, or setting up inappropriate incentives at various levels. Consulting service recipients and their carers can reduce such risks by sensitizing decision-makers to implications of various approaches (Kingsley and Towell, 1988; McAusland *et al.*, 1986).

As hospitals close and services diversify, special attention is necessary at each level to prevent neglect of people with long-term and disabling problems or others at high risk of being 'unserved, underserved or inappropriately served'. Equally vital is the challenge of preventing avoidable disablement, through effective services and support from the initial onset of mental health problems.

Which service functions are essential in every district?

Meeting priority service needs also requires clarity about service design and organisation. The 1975 'better services concept' (Cm. 6233) described services in two ways: teams of professional staff and types of service settings. Emphasis was given to district general hospital (DGH) psychiatric units, day hospitals, day centres, and hostels. All were seen as central to a complete district mental health service, and numerical targets were recommended.

There has been debate for many years, however, about a number of these concepts. Questions about service design and organisation have generated numerous articles and reports (COHSE, 1983; MIND, 1983; Richmond Fellowship, 1983; Wilkinson and Freeman, 1986; King's Fund, 1987; National Unit for Psychiatric Research and Development, 1988). These and other analyses and proposals build on the 'better services' approach in some ways, and deviate from it in others.

Among service users, there are frequent calls for different styles and types of service. Many dislike traditional service models, finding activities boring and meaningless (MIND, 1991; Rogers *et al.*, 1993). Meltzer and others (1991) found that only 23 per cent of people diagnosed as schizophrenic and eligible for day care actually used it. A particularly strong theme is dissatisfaction with responses typically provided in crisis: many groups call for 'non-medical crises houses' as an alternative to acute hospital care (Beeforth *et al.*, 1990). Other emphases include more counselling, more permanent housing with support, more real work opportunities, and more advocacy.

The *Mental Illness Key Area Handbook* provides substantive guidance on service planning. As in the case of CSS, there is emphasis on individual care planning and monitoring – organised through the 'care programme approach' and 'care management'. Indeed, in many ways, *The Handbook* is far more comprehensive than the CSS concept, because it includes prevention, treatment, and rehabilitation for all populations in need, rather than focusing on a single sub-group such as the long-term mentally ill. Of particular interest is the elaboration of nineteen potential service settings for the delivery of mental health care (see Box 12).

In addition to service settings, *The Handbook* also identifies a range of psychiatric treatment methods, such as psychotherapies, drug treatments, and ECT (See Appendix 6.3, p. 82). Housing, work, advocacy and self-help are also emphasised in several places. But no effort is made to specify essential local service functions.

In both Britain and the US, however, many mental health managers and professionals now prefer a focus on service functions, principles and desired outcomes, rather than on settings or facilities as such. For example, the CSS concept identified such functions as outreach, education and support to families, supportive housing or work opportunities and peer support – including both user-run services and self-help groups – as essential for the CSP population. The importance of such functions could easily be overlooked in an emphasis on settings.

12

SERVICE SETTINGS FOR THE DELIVERY OF MENTAL HEALTH CARE

Users' homes

Day hospitals

Crisis accommodation

Acute units

Alternatives to DGH hospital sites

Day Centres

Drop in centres

Community mental health resource centres

Unstaffed group homes/flatlets

Adult placement schemes

Private board and lodging houses

Residential care homes

Staffed group homes

Core and cluster schemes

Mental nursing homes

24 hour NHS residences

Local secure units

Medium secure units

High security units

Quoted from the *Mental Illness Key Area Handbook*, Appendix 6.1, pp. 75-77.

From a cost point of view, however, settings for acute care make an enormous difference. In recent years, the assumption that acute care should be provided in district general hospitals has been eroding, and new possibilities are emerging (Echlin and Ramon, 1991; King's Fund Centre, 1991). For example, a Northumberland steering group on reprovision of services from a mental hospital being closed has concluded:

> *location [of acute in-patient services] on a DGH site was strongly felt to be inappropriate, not least given the experience ... in North Tyneside which appears to have locked mental health expenditure into in-patient beds and reduced the flexibility to develop innovative alternatives ...*
>
> *Evidence ... shows that the DGH model tends to undermine effective integration between psychiatric in-patient and community services, whilst enhancing the less important integration of in-patient psychiatry with other DGH surgical and medical specialties* (Northumberland Health Authority, 1992, p.9).

In the US, most public mental health planners agree that very few mental health clients require intensively staffed or secure residential provision such as hospitals, either short or long-term, *if* other options are well developed – an important qualifying phrase. Richard Warner (1985), medical director of a comprehensive community support system led by a CMHC in Colorado, has suggested:

> *if community support services were provided on a truly comprehensive basis, we would only need small hospitals ... [serving] a highly specialised function. Based on experience in Boulder and elsewhere, only two or three hospital beds for adults [aged 18-60] would be needed for each 10,000 of the general population ... maybe slightly more in large cities* (p.293).

At a conference in London, leading psychiatrists from the US and Australia emphasised the need to refocus mental health provision. Instead of episodic care in the hospital and minimal support outside, leading to recurring cycles of crisis and rehospitalisation, what is needed is continuing support in the community (Stein, 1992; Hoult, 1992).

It is significant that *The Handbook* calls for 'user-friendly' alternatives to DGH sites for acute psychiatric care, along with increased use of mental health centres, hostels or ordinary housing for crisis accommodation. This contrasts with previous assumptions that the district general hospital would serve as the base from which other local provision would take place. The best organisational approach may vary, of course, according to local conditions. This was explicit in NIMH's CSS framework, calling for a local 'core services agency' to be jointly agreed by relevant state and local agencies.

As the debate continues, some advocate redeveloping the campus of appropriately located mental hospitals as a focus for 'new communities' within which a range of mental health and perhaps other activities could be housed (Kendell, 1989; Jones, 1988). Others emphasise the role of the primary health care system (GPMH, 1989). Another option is to organise local mental health services around community mental health centres (Beardshaw and Morgan, 1988; Jones, 1988).

Enhanced clinical and social recovery rates have been demonstrated through an integrated approach to primary, secondary and tertiary care. This approach involves intensive training of users, carers and professionals in relevant skills and effective intervention strategies, giving minimal attention to location or bricks and mortar concerns (Falloon, 1985; Falloon and Fadden, 1993). But the question remains: what service functions are essential in every district, and what are the best ways of organising these functions into an effective system?

From 'better services' to better futures

The Handbook creates conceptual space for innovation and provides a valuable roadmap for implementing current policies. Emphasis is shifting from services provision as an end in itself to user-led approaches meant to create better futures for people with various difficulties.

In the current climate, however, it will not be easy for purchasers to set priorities among competing population groups, professionals, providers, and service types. In many cases, funding mechanisms and budgets are likely to dictate service design, with short-term, piecemeal arrangements being the order of the day. And if US experience is any guide, many providers will quickly learn to garner available resources for what they prefer to provide – regardless of system priorities and needs.

Writing in 1972, social historian Kathleen Jones warned against 'drifting by default into the 'no-model' model of mental health care' (p.352). In the 1990s, the challenge remains to develop greater clarity about preferred service patterns. The wide variations at present, and the many options available under current policy are likely to encourage short-term and piecemeal approaches.

In these circumstances, it would be useful to conceptualise and describe the major options for service organisation as clearly as possible, and to identify their advantages and disadvantages under different circumstances. It would be helpful to organise a focused national debate on mental health service design, leading to an authoritative, but flexible, national planning framework – or set of standards – for local mental health systems. Priority sub-groups, essential and optional service functions for each group, and guiding principles could be identified – drawing on *The Handbook*, the CSS concept, other planning approaches (see Smith, 1990) and local experience. Twenty-two organisations have been working together, establishing the foundations for nationally agreed standards for 'community care' for all priority groups (British Medical Association, 1993), but the complexities of mental health require special focused consideration.

Without greater clarity and agreement about the elements of a comprehensive local service system, it is difficult to see how patchy and uneven service development can be effectively addressed. As districts increasingly 'do their own thing' it will be hard to know what is working, what isn't working and why. The momentum from the mental health strategy offers an ideal opportunity to clarify these issues, drawing on insights from the user movement.

NIMH took three years to develop the CSS concept, through the participatory process described earlier. Even in a contentious field such as mental health, a reasonable degree of consensus can be developed, drawing on research and stakeholder experience, if adequate time, attention, skill and determination are invested.

4 Leadership and accountability

Whatever the drawbacks and limitations of mental hospitals, at least it is clear who is in charge and who pays for services offered. A combination of medical care, long-term shelter, basic necessities and, in some cases, work is provided under a single administration. As these functions are dispersed, each organisation, level and sector becomes preoccupied with its own self-interest, often struggling to make ends meet by shunting difficult clients and costs off to other organisations. As in the US, no single organisation in Britain at any level has responsibility and authority to take a lead in developing local *systems* of support, housing, care and treatment for people with mental health problems. Indeed, the profile of mental health agencies is generally lower at all levels than in the US. However, unlike the US where major resources for mental health care are controlled by the states, in Britain, major funding for both hospital and community care is controlled or strongly influenced by central government. Therefore, despite recent decentralisation moves, the Department of Health is in a far stronger position than NIMH was in the mid 1970s to manage the change process and bring about widespread service improvements.

National leadership

There have been long-standing concerns, however, about inadequate accountability and leadership at a national level. Sir Roy Griffiths urged the government to appoint a Minister for Community Care (Griffiths, 1988). David Hunter and Ken Judge (1988) suggested a Community Care Development Agency. More specific to mental health, Graham Thornicroft and Geraldine Strathdee (1991) have called for a National Mental Health Commission to provide policy leadership and interdepartmental co-ordination.

The current approach, however, remains fragmented. The NHS and community care policy changes have devolved authority closer to where the service is delivered, allowing more local flexibility. Great faith has been placed in diversification and choice through bringing market forces into health and social services, although this is tempered by policy emphasis on needs assessment and the development of individual 'packages of care'. In general, however, the approach has reduced central government responsibility for whatever may go wrong.

As hospital closures continue, spearheaded by regional health authorities, responsibility for developing community care remains largely on a separate track, led by local authorities. Without coherent and sustained co-ordination at local levels, this appears to be a recipe for continued service patchiness. Local systems with exceptional leadership will continue to improve, but many others are likely to deteriorate amidst the complexity of the new policies.

In June 1991, however, the Department of Health, through its mental health strategy, has announced a more explicit leadership role (Cm. 1523), described as:

> *[monitoring and assessing] the [mental] health of the nation and [taking] the action necessary, or ensuring the action is taken – whether through the NHS or otherwise – to improve and protect health* (p.17).

This role includes stimulating a national dialogue, refining objectives and targets accordingly – 'involving people more' in decisions about priorities, and mobilising concerted action toward agreed objectives. Four additional governmental initiatives address the need for national leadership:

- a National Centre for Mental Health Services Development, launched in 1991 with government and Mental Health Foundation support, to provide consultation to statutory bodies;
- a Department of Health Mental Health Task Force, launched in 1992, including 'officers from the relevant statutory agencies', to further the development of locally-based services (Cm. 1986);
- A Community Care Support Force, launched in late 1992 by the NHS Management Executive to 'provide practical assistance to health and local authorities...in implementing the community care reforms'. This was disbanded in April, 1993, but is still considered by some to be very necessary (House of Commons Health Committee, 1993c);
- an Advisory Committee to oversee implementation of recommendations from the Reed Committee Report on Mentally Disturbed Offenders (Cm. 2088, 1992).

These, along with the work of certain independent national organisations create visible focal points for national leadership on community mental health related issues. There are additional focal points for social services, and housing. What remains lacking is a *single national focal point* for policy, planning and development efforts concerned with mental health and mental illness.

Various commentators have attempted to address this issue, including Kathleen Jones, who has advocated a fundamental reappraisal. In 1990 she commented:

> *Are mental health services moving in the right direction? In my opinion, no. Psychiatric hospitals have lost the dynamic they had ... when therapeutic community policies were widely adopted, and most local authorities have had no opportunity to develop a dynamic service.*
>
> *There is no agreement about what a comprehensive service should include ...*
>
> *What is needed: A Royal Commission (there have been none since 1979, but this is the best way of calling a group of experts together to make policy recommendations).*

Such recommendations might include, she thought, a National Institute of Mental Health, bringing together services, research and training activities, and a nationwide network of community mental health centres (Jones, 1990).

These are not the only options. One alternative to a Royal Commission would be a *Standing Conference on Mental Health,* to orchestrate continuing well-structured dialogue and joint action among the stakeholders, helping to implement current policies as effectively as possible, while identifying policy refinements needed. A series of national and regional events could be strategically designed to assess the evolving situation, identify long-term priorities for service improvements, and promote well considered joint action at all levels.

Staffed by a small but skilled secretariat, the 'conference' could involve not only recognised experts, but a wide range of users, carers and minority representatives as well – in numbers sufficient to have an impact. Such conferences could emphasise vision and values – within a systems perspective. A national 'Vision Statement' could be developed and periodically refined, implementation experience could be shared, and relationships between policy and practice could be examined in areas such as service design and organisation, quality assurance, funding, training, evaluation and research – drawing on activities of all relevant organisations.

The process could perhaps be orchestrated by the Department of Health and the Social Services Inspectorate, in collaboration with the Department of the Environment, with smaller working parties feeding into major conferences. Another option would be for one or a consortium of independent national organisations to take the lead, working in partnership with user and carer groups on the one hand and with management, voluntary, professional and statutory bodies on the other. Whether or not government sponsored the series, key officials would need to participate, listen and respond to emerging concerns. And a long-term commitment would be vital for the effort to make a real difference.

Regional leadership

Because mental hospitals serve multiple districts and localities, many critical issues demand strategic attention at regional levels as well. In the US, state mental health authorities accountable to their populations serve this role. England's mental health strategy states that regional health authorities:

> *should take the lead where necessary in promoting the development of a strategic framework by 1994/5 for the development of comprehensive locally based services to replace dependence on inappropriate provision in large outdated institutions...* (Cm. 1986, p.88).

In principle, this allows scope for RHAs to assume a development role similar to that of US state mental health authorities, described in Box 6. The Welsh Office in its strategies for mentally handicapped people (1983) and people with mental health problems (1990) has assumed similar functions.

The strategic role of regional health authorities has been reaffirmed recently by the Secretary of State for Health (Bottomley, 1993), although drastic staff cuts are being considered. In England, however, structures, funding arrangements, and long-standing mistrust between central and local governments complicate regional leadership roles (Audit Commission, 1986).

Local leadership

At local levels, the mental health strategy emphasises the strategic role of district health authorities (DHAs), working in partnership with other statutory, voluntary and private agencies. The new health, mental health and community care trusts, too, have a local leadership function. Further complicating the picture, Family Health Services Authorities (FHSAs) have lead responsibility in primary care, and local authorities (LAs) have lead responsibility under the NHS and Community Care Act 1990 for community care for all 'priority population groups' including people with a mental illness. In planning a 'seamless service' one commentator has suggested that:

> *the local authority must be the key agency around which services are to be designed if we are to make the best use not only of social services but also of housing, education and leisure facilities'* (Murphy, 1991, p.140).

Some districts have a tradition of collaboration between health, social and housing agencies. Where key actors have a sense of common purpose, and where geographic boundaries are not too problematic, they continue to get on with the job, without awaiting further edicts from Whitehall.

Ambiguities remain, however, about health and social services responsibilities. And new complexities are emerging as the functions of purchasers are split from those of providers. Despite the difficulties of working across governmental levels and sectors there seem to be no viable alternatives. CSP's multi-level approach therefore has some relevance in the British context (Turner and TenHoor, 1978; Tessler and Goldman, 1982). This suggests a need for active development assistance to bring local agencies together around shared goals.

Moral versus formal responsibility

In some circumstances, assuming moral responsibility for the whole of a complex situation, beyond the limits of an organisation's formal responsibility, can offer a way forward. For example, the CSP initiative acknowledged that responsibilities and funding in the US were likely to remain fragmented. By forming a new partnership with states, NIMH sought to establish moral leadership at each level in meeting the needs of a vulnerable population. The focus on quality of life generated a sense of common purpose, and the CSS concept provided a common language for pursuing it.

No government level or sector has assumed a clear moral responsibility in Britain for the general welfare of people with serious mental illness. Instead of promoting co-operation to ensure that what is vital *will* be done to address shared concerns, current policies tend in some ways to encourage each organisation to define what it will *not* do or pay for. Nonetheless, some statements in *The Health of the Nation* suggest that the Department of Health may be prepared to assume a moral leadership role in ensuring that comprehensive needs of people with a mental illness are better met.

However, US experience has also demonstrated the limits of exhortation and voluntary collaboration in the absence of appropriate legal authority and fiscal policies. Fundamental structural and funding arrangements often present major obstacles to policy goals, and must be adequately addressed if reform efforts are to achieve the desired effects. Recognition of this led the Robert Wood Johnson Foundation to launch its Demonstration Programme on Chronic Mental Illness in 1985. The ultimate aims were similar to those of CSP; the means were competitive grants directed towards fiscal and structural reform. Five-year demonstration projects were launched in nine major cities, establishing a 'single point of administrative, clinical and fiscal responsibility – a local mental health authority'. In addition to mental health treatment, authorities sought to ensure adequate housing, social support and rehabilitation services for the population of concern (Cohen and Shore, 1990; Goldman *et al.*, 1992).

In Britain, many are advocating that health and social service resources be pooled through 'joint buying consortia', to overcome structural and funding difficulties (Murphy, 1991). Indeed, this would reduce certain barriers that make it difficult to respond to individual needs. Joint purchasing is specifically recommended in *The Health of the Nation:*

> *All district health authorities, family health service authorities, local authorities and relevant voluntary bodies will need to establish joint mechanisms for purchasing local services, including supported housing, and for ensuring that they deliver continuity of health and social care* (Cm. 1986, p.88).

To establish joint purchasing on a widespread basis will require both DHAs and local authorities to give up a certain amount of control over resources. Legal mandates or incentives may be required and conflicting geographical boundaries may remain problematic.

As purchasing strategies emerge, there is an urgent need to develop and support a cadre of people in strategic positions – at local, regional and national levels – with authority, vision, commitment and skills to provide leadership in a constantly challenging environment (Audit Commission, 1992). The CSP mobilised a nationwide cadre of 'change agents', focusing initially on state mental health authorities, and created a national network to facilitate collaboration across boundaries. Who are the primary local and regional 'change agents' in Britain who can develop coherent systems of support, housing and care for people with mental health problems? And what more can be done to equip and support them for their crucial role?

5 Incentives and leverage

In the US, certain funding mechanisms have had an unintended and negative impact on the shape of services, and have distorted service priorities. Hospital-based or medically-oriented services fundable from Medicaid and insurance programmes have spread; alternative services, no matter how valuable or necessary, have remained under-developed (Torrey, 1990). In recent years, however, various national and state initiatives to improve incentives have begun to show encouraging results (Mechanic and Aitken, 1989; Miller and Rago, 1988; Goldman *et al.*, 1992).

As noted in Part 1, British policy makers have recently modified a perverse incentive toward over-use of residential care. From April 1993, the care element of residential funding was transferred from the social security budget to local authority social services departments. By allowing these funds to be used for either residential or domiciliary services, and by requiring that individuals be assessed before going into residential care, the incentive toward over use of sheltered settings has been reduced.

A modest specific grant to provide pump-priming resources and the decision under pressure to 'ring-fence' all the funding being reallocated from residential care have been welcomed by mental health leaders. But many fear that community care resources will remain inadequate (Social Services Committee, 1990b; Ivory, 1993; Health Committee, 1993). And it is clear that if coherent service systems are to emerge in every district and locality, further improvements will be needed in purchasing strategies, fiscal incentives, budget holding arrangements and resource allocation strategies, as well as in funding levels.

Purchasers as catalysts for system improvement

The separation of purchasing from provision is seen by some as a major opportunity to create more cost-effective and responsive services. Clearly, purchasers play a major role in service design and development – exercising 'leverage' over provider activities. Whether or not contracting for care will bring greater consumer choice, it does offer opportunities for greater clarity about services, desired outcomes and costs (Common and Flynn, 1992). At best, purchasing can be used strategically to create area-wide service systems, focusing on those most in need. If budgets for health and social care are placed under joint management, resources can be better used, and incentives to refer people elsewhere can be reduced.

Purchasing also offers opportunities to support user-run, self-help and other innovative projects, including for example, the crisis houses advocated by some service users (Beeforth *et al.*, 1990) and the respite care advocated by some carers. Purchasing district-wide services for people suffering from mental distress or illness is far more complex and subjective, however, than purchasing cataract or hip operations. Considerable judgement, expertise and skill is required to orchestrate the 'appropriate balance of prevention, treatment and rehabilitation' called for in the mental health strategy (Cm. 1986, 1992). Purchasing decisions must also be co-ordinated with related activities of housing, employment and criminal justice agencies. And effective ways must be found to bring service users, carers, and minorities into decision-making.

All this requires that purchasers think clearly about populations of concern; their service needs and preferences; the distinctions between need, demand and use of services; the range of residential and non-residential services options that can be developed; the distinctions between service components, programmes, and systems; the social control functions of mental health care; the balance between individual, family and community needs and rights; and research about costs and benefits of different 'packages of care' for various populations. Measuring service outcomes (Jenkins, 1990), and ensuring quality of care (Dorward *et al.*, 1986) are additional challenges in mental health purchasing.

If purchasers are to fulfil their potential as 'champions of the people', the purchasing function will need strengthening (Ham and Matthews, 1991). Purchasers will need training, supervision, support, and adequate authority or 'clout'. They will also need skills in consultation and planning, and an understanding of how to use leverage to stimulate service improvement, for example through 'incentive contracts' (Frank and Goldman, 1989). In addition, incentives may be needed to encourage a focus on area-wide system building – perhaps through criteria for purchasers' performance review.

Substantive guidelines and good practice statements are also important, drawing on consumer experience, model programmes and research. And purchasers need the means to keep abreast of emerging knowledge, balance stakeholder concerns, encourage good practice, and gradually shift resources to more effective patterns of care.

Success in reshaping mental health and related services will depend in considerable measure on the extent to which mental health purchasers nationwide are equipped and supported in their role. A network of mental health purchasers is exchanging information about such issues. In addition, both the US and Britain could benefit from a well-structured, ongoing dialogue about purchasing for mental health gain.

Fiscal incentives for systems improvement

It can be argued, however, that present policies place too much burden on purchasers alone for innovation, equity, system design and system coherence. Broader incentives and leverage are needed from central or regional levels as well, with special attention to reallocating resources from hospital closures.

The inadequacy of incentives for district health authorities and social services departments to work together and for local authorities to develop community services has frequently been noted (Audit Commission, 1986; O'Donnell, 1989; Wistow, 1990). Although the NHS retains clear responsibility for health services in the community, lead responsibility for community care is assigned to local authorities. This term is sometimes described as a 'misnomer' (Hudson, 1991) as it could appear to let the NHS off the hook. Certain advantages of shifting towards a more social model of mental health care are widely recognised. But it is also recognised that SSDs will be hard-pressed to fulfil their responsibilities concerning people with mental illnesses.

At present, many SSDs lack experience of dealing with serious mental illness in community settings; much of the expertise and commitment to this remains in the NHS. Local authority specialist skills in psychiatric social work have been eroding for many years, in part because of a reorganisation in the early 1970s, after the Seebohm report recommended a generic approach to social work (Cmnd. 3703, 1968). Since then, social work has been independent of medicine, and local authority social workers have concentrated mainly on children and to a lesser extent the elderly. Demands of the Children Act 1989 place additional burdens, and local authority activities concerning mental illness are hampered by funding shortages, rate capping, and pressures from other priority population groups. In 1987, local authority social services departments accounted for less than four percent of the total NHS and personal social services expenditure for people with a mental illness (Taylor and Taylor, 1989).

Governmental worries about the impact of community care policies on local tax burdens have already led to a two-year delay in implementation (Henwood *et al.*, 1991). A review of local government structures (Department of the Environment, 1991), and implementation of the new council tax present additional uncertainties about the local authority 'lead role' in community care (Hudson, 1991; Institute for Public Policy Research, 1991).

The CSP approach to local leadership was to recognise that each region (state) and locality was in a different stage of development. Therefore, states and localities were asked jointly to designate a local 'core service agency' – taking resources, geography, leadership, and other factors into account. A flexible approach would be worth considering in the British context. A few local authorities may be ready now for a 'lead responsibility' in community care of people with mental illness; others probably are not.

CSP strategy development and demonstration projects also provided fiscal and other incentives for states to view service development strategically and comprehensively. CSP funds helped states stimulate and assist localities with five-year development programmes, reallocating resources from hospital systems where possible.

In Britain, a nation-wide network of 'change agents' could be created by strengthening the RHA role in system building. Each region could establish a 'transition team' with officers from the Department of Health, the Social Services

Inspectorate and other relevant bodies. Modest resources could be set aside at national level or in the regions for competitive and well-targeted grants or contracts to promote local system improvement, involving stakeholders in the planning process and leveraging both hospital and community resources. This would increase incentives for local system development and could have a multiplier effect in directing resources to more effective use.

At present definitional problems concerning health and social care are likely to perpetuate conflicts between statutory authorities – particularly where mental illness is concerned – offering inadequate incentives for effective joint working. Creative approaches to budget-holding and joint commissioning, however, offer prospects for overcoming some of these difficulties.

Budget holding and resource allocation

Whether resources from hospital closure are being effectively channelled toward community care is another matter of concern (QSRE, 1989). In some cases, in the past, new residential, day and other services have been supported in considerable part from NHS budgets redirected from mental hospitals. David King (1991), who managed a hospital closure and development of community services in Exeter, has underscored the value of ring-fencing funds released from hospitals and of having the people closing hospitals also responsible for building up community services. Under the NHS and Community Care Act 1990, however, methods for transferring resources from hospital to community remain inadequate.

One way of handling such issues is through budget holding arrangements or resource allocation procedures. An early and successful US change in budget holding was Wisconsin's 1973 legislation requiring every county to plan for and provide (or purchase) services for the mentally ill. The key innovation was to combine budgets for both in-patient and community services, making it easier to reallocate funds between the two. This provided an incentive for counties to avoid inappropriate use of hospitals and use the savings on community services development instead (Stein, 1989). Other states have adopted similar approaches (Miller and Rago, 1988).

Another approach is for central or regional bodies to link resource allocation procedures to clearly-defined performance criteria, in contrast to relying mainly on population-based allocation formulae. Pennsylvania's mental health authority successfully used allocation criteria to stimulate county mental health agency efforts towards four specific service development goals. These included: reducing the need for hospitalisation; shifting from an acute-care approach to a community-based, rehabilitative approach; being accountable to the state; and providing cost-effective services (Hadley *et al.*, 1983). Funding was contingent on counties addressing these objectives.

In Wisconsin it was noted that 'although a funding strategy can facilitate change from a hospital-based to a community-based system, such a strategy is not in itself sufficient to ensure that change' (Stein, 1989). Special purpose funding is also needed for capacity-building; equally important is a development role.

Problems in Britain about the care of 'mentally disordered offenders' relate to budget-holding arrangements. Government policy specifies that in principle, their care and treatment should be provided by the NHS and social services. But strong fiscal incentives remain for the NHS not to treat them, but to refer them to the Special Hospitals Authority or to prisons instead. A possible way round this would be to make DHAs financially responsible for psychiatric treatment of such clients from each district, regardless of who provides their care (Cm. 2088, 1992).

The Social Services Committee (1990c) has emphasised the need for 'a co-ordinated and agreed strategy that carries with it an allocation of appropriate resources' (p. xxxviii). Budget holding, allocation procedures and incentives must also be carefully considered and leverage must be applied at the right levels to bring about widespread service system improvements.

6 Learning from experience

There is strong impetus for 'getting on with the job' of implementing the NHS and Community Care Act. For many reasons, however, a thoughtful, experimental approach to implementation efforts is needed to the extent that pressures permit. Policy goals and strategies need clarification. And well-defined procedures are needed to distil and disseminate lessons from experience, as the basis for incremental improvements in policy and practice.

The importance of listening to and learning from consumers of an organisation's services is now widely accepted (Peters and Waterman, 1984). Experiences of mental health services recipients and their families are particularly instructive in understanding what helps and what hinders abilities to cope with or overcome mental illness or distress. In the US, this has been recognised in a resolution by the National Association of State Mental Health Programme Directors (1990).

Management experts are also emphasising that the capacity of any organisation or system to learn continuously from experience is central to its effectiveness. Peter Senge (1990) has identified 'the five disciplines' or skills relating to organisational learning – ideas that are relevant to the entire mental health enterprise, in Britain and elsewhere:

- personal mastery: 'clarifying the things that really matter to us, and living our lives in the service of our highest aspirations' (p.8);
- building shared vision: 'translating individual vision... into shared pictures of the future that foster genuine commitment and enrolment, rather than compliance' (p.9);
- being aware of 'mental models', which are 'deeply ingrained assumptions, generalisations, or even pictures or images that influence how we understand the world and how we take action' (p.8);
- systems thinking: keeping the big picture in focus, rather than focusing on events, snapshots, or isolated parts of the system (p.9);
- team learning: which 'starts with dialogue, the capacity of members of a team to suspend assumptions and enter into genuine thinking together' (p.10).

As mental hospitals close and strategies are devised for community care, there are exceptional opportunities for learning from experience, clarifying what does and does not work under different circumstances and developing principles to guide future work. For example, mental health services are being incorporated into independent trusts in a variety of ways: as mental health trusts, as mental health and learning disability trusts, or as part of wider health trusts (Sayce, 1992). Case management is being organised in a variety of ways (Onyett, 1992). A variety of arrangements for purchasing is being established.

Such opportunities can be fully used for learning only if they are clearly recognised. Various regional and local service development approaches should be conceptualised, and hypotheses developed about the best strategies for various circumstances; these can then be examined through analysis, evaluation, research, and dialogue amongst people with similar responsibilities. A well-structured stakeholder network would be another way of distilling such lessons. In these ways, the pros and cons of various approaches can be better understood and disseminated.

Another method for systematic policy refinement while getting on with implementation is the 'evaluability assessment' described in Part 2. An evaluability assessment would be useful in Britain in clarifying intended outcomes and unintended side-effects of various aspects of mental health policy, bringing a systems perspective to a set of complex and related issues. This could provide a sound basis for policy refinements.

A thoughtful, experimental approach to implementing the NHS and Community Care Act could improve both policy and practice, and lay the foundation for more effective long-term approaches. Collaborative research with the US could be of mutual benefit, focusing, for example, on some of the service systems issues identified in the national plan of research to improve services for people with severe mental disorders (NIMH, 1991).

Work is underway in Britain on all six of these critical issues. Whether momentum increases for service improvements will depend in large measure on how effectively these six issues are managed.

Conclusion: emerging opportunities

In both the US and Britain mental ill health creates immense burdens for individuals, families and society – underscoring the importance of sound mental health policy. As both countries struggle with a massive systems transition, the challenge is to reshape mental health and related services in a way that empowers users, carers and service workers. This means mobilising diverse resources on a major scale, in a manner that is sensitive to individual, family and community concerns (Fransen, 1991).

In both countries, about two thirds of public mental health funding remains tied up in hospitals, although most mental health care has shifted outside. Both countries are struggling with recession, housing problems, and numerous competing priorities. And in both countries, changing ideas about mental illness and health, changing relationships among the key actors, and changing structures and funding mechanisms complicate efforts toward service development. In this atmosphere, whether mental health services (or parts of those services) develop coherently or disintegrate remains a matter of concern and continued debate.

Meeting the challenge requires coping creatively with ambiguity, complexity, negative professional and public attitudes, vested interests, reluctant collaborators, outmoded structures, resource shortfalls, dysfunctional funding mechanisms, and many other obstacles. US experience with the Community Support Programme suggests, however, that such issues can be approached at any level – national, regional, or local – through focusing on the following:

- *clarifying the vision of what needs to happen;*
- *involving stakeholders;*
- *applying a systems approach;*
- *mobilising effective leadership;*
- *realigning budget holding, fiscal incentives, and structures, as needed;*
- *and facilitating continuous learning from experience.*

The CSP initiative initially applied these ideas to services for adults being neglected in the aftermath of unplanned deinstitutionalisation. The approach applied at the national level was also adopted by states and by many local districts. By 1983, five years into the initiative, the CSP / CSS model had demonstrated its value. Stakeholder groups persuaded NIMH to develop a similar initiative – the Children and Adolescent Service System Programme (Stroul and Friedman, 1986; Mental Health Policy Resource Centre, 1990). By 1987, many aspects of the CSP approach had been written into national mental health planning legislation and guidelines (NIMH, 1987).

In Britain, the current process of change involves the entire mental health system and related 'community care' services, not just services for particular sub-groups. As the programme of hospital closure continues, the mental health strategy (Cmnd. 1523; Cm. 1986) has been superimposed on to a major system change stemming from the NHS and Community Care Act 1990. And all this in addition to pressures for change from users and carers.

In both countries, listening to current and former service recipients often challenges managers and professionals to re-examine their ideas about the nature of the enterprise. For example, consumer / user and mutual-help leaders are challenging the assumption that a sharp dividing line can be drawn between 'problem people' and 'solution people'. One mutual help organisation with thirty years' experience in the US, Ireland, Australia and other countries views mental health and mental illness in the way described in Box 13.

Through weekly educational and support groups, GROW members help one another combat forces of disintegration and choose personal growth. Research shows that after nine months in GROW, members (about half of whom had extensive psychiatric histories) had fewer symptoms, more friends and were more likely to be employed (Rappaport *et al.*, 1985). The mutual help process is regarded by GROW as *'primary empowerment'* in contrast to advocacy for rights, benefits or services, which they see as *'secondary empowerment'* – also a much needed objective.

Empowerment of one form or another is becoming a theme for mental health services – on both sides of the Atlantic. Dan Fisher (1991), a US psychiatrist who has recovered from mental illness and is active in both consumer and professional organisations, regards mental illnesses as 'developmental disorders of the self', arising from a combination of factors. For him,

> *the essence of empowerment ... is to develop and harmonise as fully as possible our powers in the biological, emotional, mental, social and spiritual realms* (p.69).

13

A MUTUAL-HELP ORGANISATION'S PERSPECTIVE ON MENTAL HEALTH

The line between
mental health and mental illness,
moral goodness and moral badness,
... love and selfishness,
sound drug use and drug abuse,
community-building and community destroying,
does not pass between this and that discernible group in society,
but ***down through the heart of every single one of us.***

It varies and fluctuates at different times,
according as one or other of two
continuously active and opposite processes ...
personal growth and personal disintegration ...
is currently dominant in our lives.

(GROW International, 1983).

In the US, some see empowerment as part of a wider organising concept for mental health services: *facilitating recovery.* Within the CSP network, growing numbers of 'consumers' are telling stories of substantial recovery from devastating problems. (See, for example, Anonymous, 1989; Balter and Katz, 1987; Deegan, 1988; Leete, 1989; Lovejoy, 1984; Unzicker, 1989). William Anthony (1991) defines recovery as:

> *a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles ... a way of living a satisfying, hopeful and contributing life even with illness-caused limitations* (p.13).

Rae Unzicker of the National Association for Psychiatric Survivors expresses the idea like this:

> *... [a] new mental health word, not yet totally accepted, [is] gathering momentum ...* ***recovery*** *... not just maintenance and ... community baby-sitting, not just getting people to take their drugs and sustain themselves at a minimal ... level, but* ***recovery*** *– permitting people to live full and rich lives, like others who overcome different catastrophic illnesses* (Mental Health Policy Resource Centre, 1992, p.13).

Ideas are also changing about what professionals, families and other helpers can do and what service systems should offer to facilitate coping and recovery (Hatfield, 1989; Anthony 1991). In the US, the CSS concept reflected a paradigm shift from clinically-oriented approaches toward a 'bio-psychosocial' one (Turner and TenHoor, 1978), combining natural helping processes with application of professional skills in rehabilitation, social work, psychology and psychiatry. From a focus on clients alone, the concern of US mental health planners has expanded to include support to families and community members as well. An emerging consensus toward this way of thinking (Bloche and Cournos, 1990) has facilitated service improvements, and ideas are continuing to evolve.

In Britain, too, new ideas are emerging from interaction of policy makers, managers, service users and carers, professionals and others. For example, a recent House of Commons Health Committee report on proposals for 'community supervision orders' supported ideas emerging from the experience of service users – recommending among other things that the use of 'crisis cards' be encouraged both in practice and in law. This would permit individuals to specify in advance, during periods of functioning well, what they wish to have done in a psychiatric emergency, perhaps in some cases obviating the need for compulsory hospitalisation. (See House of Commons Health Committee, 1993c.) The 1993 *Key Area Handbook on Mental Illness* also reflects new insights, to be refined as the dialogue continues.

There are, of course, no perfect organisational or policy solutions to human distress and dysfunction. Continuous adaption is required to incorporate new insights and adjust to changing circumstances. Nor does any single profession, sector or interest group have the answers. Nonetheless, many positive things are happening in both countries, leaving ample room for further and continuous improvement.

Even within complex and sometimes dysfunctional systems, individual and small group initiatives can and do make a difference – and often have a significant ripple effect. Edward de Bono's description of *'Effectiveness Groups'* in his popular *Handbook for the Positive Revolution* (1991), offers useful ideas for planning such initiatives. In his view, 'the positive revolution is not centralised, but is based on the work of individuals and groups' (p.61). Indeed, the reshaping of mental health and related services within organisations, planning districts, regions, and nations depends in large part on whether enough individuals in key positions are able to work effectively with others to overcome the inevitable obstacles that arise.

User/consumer involvement activities on both sides of the Atlantic illustrate the value of the mutual helping process that can be developed in small groups. Of course, mutual help groups cannot *replace* properly funded public services. But they *can* offer a missing link in mental health care – friendship and continuing support. This aspect of the recovery process deserves much greater attention. At the same time, it remains essential to ensure that reliable services are continuously available for the many people who for periods of time – sometimes long periods – seem entirely unable or unwilling to help themselves. The necessity for secure provision for some, and the limits of what can be expected from families and friends must also be taken into account in designing such services.

On both sides of the Atlantic, the old, disabling approaches to mental disorder are gradually being transformed. Central to the process is dialogue and community building among the different sectors of 'the mental health family'. Through combining a range of perspectives, new insights can emerge, and all participants can be given opportunities to contribute more effectively. In the process, synergy develops – with the whole effort becoming greater than the sum of the parts.

Listening to users and carers about what helps and hinders their efforts toward coping and recovery is particularly important – offering possibilities for reducing expenditure on ineffective or damaging interventions. And the stories of growing numbers of people who are recovering or have recovered remind us that we must never give up on anyone – no matter how sick or disabled, disturbed or disturbing that person may appear.

Nurturing and supporting these transformational processes, currently at work in many places, is the key leadership task for the 1990s and beyond. Ultimately, it is through such processes at every level that opportunities can be enhanced for people with mental illness or disability to find their inner balance, cope with or overcome their difficulties, live more satisfying lives, and in many instances, bring hope and encouragement to others.

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