Enabling Community Integration

The role of public authorities in promoting an ordinary life for people with learning disabilities in the 1990s

DAVID TOWELL & VIRGINIA BEARDSHAW

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CONTENTS

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David Towell

Virginia Beardshaw *June 1991*

1

Introduction

1 Introduction

Since the Second World War there has been widespread support for the view that the State has responsibility for promoting the welfare of its citizens, typically through benefits and services financed – and usually delivered – by public authorities. This welfare role has included a particular responsibility for ensuring that the most vulnerable members of our communities receive the support necessary to participate fully as citizens.

Despite good intentions, however, public services used by us all – like education and health care – have fared better in terms of quality and public esteem than those used mainly by vulnerable minorities. Indeed, there is a sense in which the sacrifices to autonomy, segregation and stigma commonly associated with specialised provision for vulnerable people actually serve to reduce rather than promote citizenship. As a result, there has been a growing debate about the *forms* that public provision should take.

During the 1980s, the increasing polarisation of politics in Britain weakened the previous consensus in support of the welfare state. Combined with a lengthy period of poor national economic performance, this has produced a hostile financial climate for attempts to improve services.

Prospects for the 1990s remain uncertain, but whatever the political scenario it seems safe to predict that people who depend on publicly financed services, and those who work in them, face a continuing struggle to achieve worthwhile objectives. The authority members, managers, service providers and consumer advocates who accept responsibility for leading these struggles locally need to do so in a spirit which promotes positive aspirations and mobilises wider commitment, while working pragmatically to make the best of any opportunities which emerge. They need to ensure too that the human and financial resources available are employed to best effect.

Setting direction

In meeting this challenge, our analysis of local experience in recent years suggests the value of combining two important strands of thought about public service development into a purposeful philosophy of change. The first of these is the notion of public agencies as *enabling.*

As always, there are narrow versions of this idea. Some amount to little more than a rationale for contracting out existing public service provision. More radical interpretations argue that while the principles of publicly-financed provision inherited from Beveridge remain largely apposite, the bureaucratic (and sometimes paternalistic) forms that post-war public support has taken need rethinking. This involves the public authorities in shifting their role from that of administrative agents for centrally-defined provision to one where they could become more effective instruments of local democracy. As such, they would use their power and authority to enable communities and interest groups to meet challenges in ways which reflected their own wishes.

The second and complementary theme is that of *community integration*. Again, there are narrow versions of this idea. Some of these look dangerously like leaving people to fend for themselves unaided. There are also fanciful versions which ask more of spontaneous neighbourliness than most of us living in late 20th century British communities would find either safe or realistic.

Between these extremes, however, it does seem vital to recognise that public services should aim to support – rather than supplant – people's informal relationships. Wherever possible they should enable disadvantaged people to establish or maintain the kind of lifestyles valued by their fellow-citizens. This is particularly important for people who may need support for long periods.

Taken together these two ideas provide the basis for conceptualising a central purpose of public agency as being – to repeat the title of our report – that of *enabling community integration.*

Better lives

Nowhere is this idea more powerful – and nowhere is the contrast with past performance so great – as in services for people with learning disabilities. It is not too long ago that the main choices available to 'the mentally handicapped' amounted either to life-long dependence on parental support or exclusion from society through admission to permanent institutional care – with, of course, a move from the first to the second of these 'options' when parents were no longer able to cope. This was particularly true for the three or four people in every 1000 with more severe disabilities.

The last 25 years has seen welcome changes in this pattern. The 1980s, in particular, have been marked by growing support for a principled approach which recognises people, whatever their disability, as fellow citizens and potential contributors to society, and seeks to ensure they have the opportunities and support necessary to lead *an ordinary life.*

We can illustrate these trends best by referring to the lives of two people we know well.

Pat Towell (David's sister) was born in 1937. As a baby, Pat caught whooping cough. The disabilities which arose from the resulting brain damage made it very difficult for her parents to look after her at home when the next baby arrived. In 1945, their only other option was to put her in hospital.

As a result, Pat has lived in institutional care for the last 46 years. For most of that time she spent empty days on the wards of buildings erected in the last century and slept in dormitories with thirty or forty others.

Pat is now a pleasant middle-aged woman. She still lives within an institutional complex but for the last ten years she has made her home in a 12-place bungalow. As plans to close the institution proceed, there are some prospects that she might soon move to an ordinary house, where she would live with staff support.

Jessica Cahn (Virginia's daughter) was born in 1983. She made the mistake of arriving in the world many weeks ahead of schedule and has since had to work very hard – with intensive therapeutic help – to acquire skills, like walking and speaking, which other children find much easier.

Today, she and her younger brother attend the local primary school, three streets away from their family home. There, with skilled help, she is learning with enthusiasm together with her peers, even though she finds it difficult to express herself and has problems in relating to other children. She pedals to school on an adapted tricycle, and uses it in the playground. She sometimes goes to the after-school club that many of her classmates use, and is about to join the local Brownie troop.

Our hope – and intention – is that the supports offered to Jessie will never require her to replicate the negative aspects of Pat's experience and that Jessie and Pat will, respectively, achieve adulthood and 'retirement' as valued members of the community.

Towards 'an ordinary life'

The King's Fund has played an important role in promoting these changes for all people with learning disabilities. Throughout the last ten years we have had the opportunity both to support and learn from people across Britain who are working to develop local innovations which demonstrate what the *an ordinary life* principles mean in practice. This has been a period of significant achievement, particularly in the spread of better opportunities and services for individuals and small groups within the community.

However, the experiences of the great majority of people with learning disabilities and their families fall significantly short of the modest aspirations – such as ordinary domestic life; worthwhile work or daytime occupation; skilled support with learning – which these achievements have encouraged.

In the 1990s, local and health authorities, together with other interests, still face a major challenge in addressing the needs of all the people with significant learning disabilities within their boundaries. Moreover, this challenge is now posed within the changing context for public services emerging from the *Children Act* 1989 and the *NHS and Community Care Act* 1990, as well as wider uncertainties about the future organisation of local provision.

Learning about strategic change

Anticipating this challenge, in 1986 the Joseph Rowntree and Mental Health Foundations commissioned the King's Fund College to undertake a four year action research programme exploring large-scale change in opportunities and services for people with learning disabilities. As Appendix 1 describes more fully, this programme has enabled us to work directly with the members and senior officers of local and health authorities and with representatives of user and community interests in a score of places, both here and overseas. Our aims have been to:

- assist public agencies in designing and implementing concerted strategies for developing community-based provision;
- draw and disseminate lessons from this work about how informed change can best be achieved; and
- identify implications for national policies.

Our focus throughout has been on the lives of people with learning disabilities and their families. We believe what we have learnt from this work has wider relevance to the way that public authorities exercise their enabling role on behalf of the most vulnerable members of the community.

The programme has contributed directly or indirectly to some thirty publications on particular issues or reporting experience from different places. Earlier King's Fund publications (notably *An Ordinary Life In Practice,* published in 1988) have described more fully the kinds of opportunities and services which are resulting in a more genuine form of community living for children and adults with severe learning disabilities. We summarise this work in offering a vision of the outcomes sought from the new patterns of publicly financed provision.

Our central focus here is on the *processes* involved in achieving large-scale change. What kind of leadership is required from public authorities? How can users of services and their advocates be involved? What is being learnt about effective ways of planning, financing and providing new patterns of opportunities and services? How can the transition from traditional services best be managed? What are the implications for staff development? How can safeguards for quality be strengthened? Our aim is to draw together the lessons that people round the country have been learning through efforts to answer these questions, and thereby provide a set of tools for constructing both robust and effective local strategies.

In this report we have concentrated on positives. A fuller account of progress in each local situation would necessarily reveal both strengths and weaknesses in the approaches which have been adopted, and considerable limitations in what has so far been achieved. At best, all the authorities with whom the programme has collaborated are still working towards radical change in the inherited patterns of opportunities and services. Looking across authorities, however, it is possible to identify with increasing confidence the different elements which need to be brought together to maximise prospects for success. We have also sought to extrapolate from local experience over the last four years to suggest how the most promising approaches may need to be adapted to the changing legislative context, and trends towards a 'mixed economy' of welfare.

In presenting this analysis we have tried to abstract wider lessons from particular examples and offer a fairly comprehensive picture of what is required. We recognise, however, that leaders in different places start from different situations and that not everything can be done at once.

Guide to the report

This report is therefore intended to be read as a diagnostic guide for local strategists. It offers a 'map' of the terrain and 'signposts' to promising routes. In the light of local priorities it also provides more detailed suggestions about how best to 'travel'. It is in four parts.

Part two, which follows this introduction, expands on the challenges faced by local public agencies. These define both the context and the need for large-scale change. We then present an *overview* of the different strands of activity which need to be woven together to generate authority-wide strategies for progress. This is the diagnostic guide.

In part three, we examine seven *key elements* in these strategies in more detail, providing succinct examples – the majority from adult services – of what has been done in places where the programme has offered assistance. Each section seeks to offer practical ideas for shaping particular sorts of local action.

Part four draws from this analysis a summary of implications for *national policies* if government is to provide a more positive framework for local action during the 1990s. This is expressed in the form of a letter to the Secretary of State for Health.

As this agenda suggests, the report is addressed primarily to members and senior officers of local and health authorities – the people with the primary responsibility for strategic leadership in enabling community integration. As we make clear however, achieving principled change necessarily involves a coalition of political, managerial and provider interests. It also depends on the development of effective partnership between public agencies and community interests – particularly people with learning disabilities, their families and friends. We have tried to write in a way which will be accessible to this wider group of people, while also seeking more direct ways (for example, through meeting People First representatives) to discuss relevant conclusions with people with learning disabilities.

From reflection to action

In our analysis of policy, strategy and systems, we have tried never to lose sight of the fundamental importance of *personal leadership* in securing positive gains for and with people with disabilities. While this is obscured in the language of White Papers and disguised still further in textbooks on public sector management, it is clear that the central requirement in building local strategies for change is that some people with representative or managerial authority make a particular effort to keep in touch with the reality of what some individuals with learning disabilities are experiencing; recognise the urgency of their situation; and engage passionately in the search for better ways of promoting community integration.

For all of us, such personal leadership needs to start from our own values, the experiences of people we know, and our assessment of the opportunities and constraints on local strategies for achieving better lives. This report offers a framework for thinking about these issues and seeks to distil lessons from the successes and disappointments of the people and authorities we have assisted. It is essentially an *invitation* – to test, modify and develop the ideas here in the light of the reader's own values and experiences, with a view to shaping local action.

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Achieving strategic change: an overview

2.1 The current challenge

The evolution of policies for 'community care' in Britain has been both slow and uncertain. For at least two decades, however, a central theme has been a desire to shift away from reliance on segregated solutions towards a pattern of support which enables people to maintain their ordinary roles and relationships. The White Paper *Caring for People* provides a recent expression of these aspirations, emphasising greater independence for people with disabilities – whenever possible through support at home – and increased control over their own lifestyles.

In relation to people with learning disabilities, progress in recent years has been characterised by two complementary trends. The first is a widespread recognition that local provision should be planned on the basis of explicit principles which start from the right of people to live as normal a life as possible in the community. The second is a flowering of innovative services – typically quite small in scale – which aim to demonstrate these principles in practice.

As noted in the *Introduction,* the King's Fund has itself been influential in these changes through its *an ordinary life* initiative. A working paper published in 1980 defined the goal as being to see people with learning disabilities

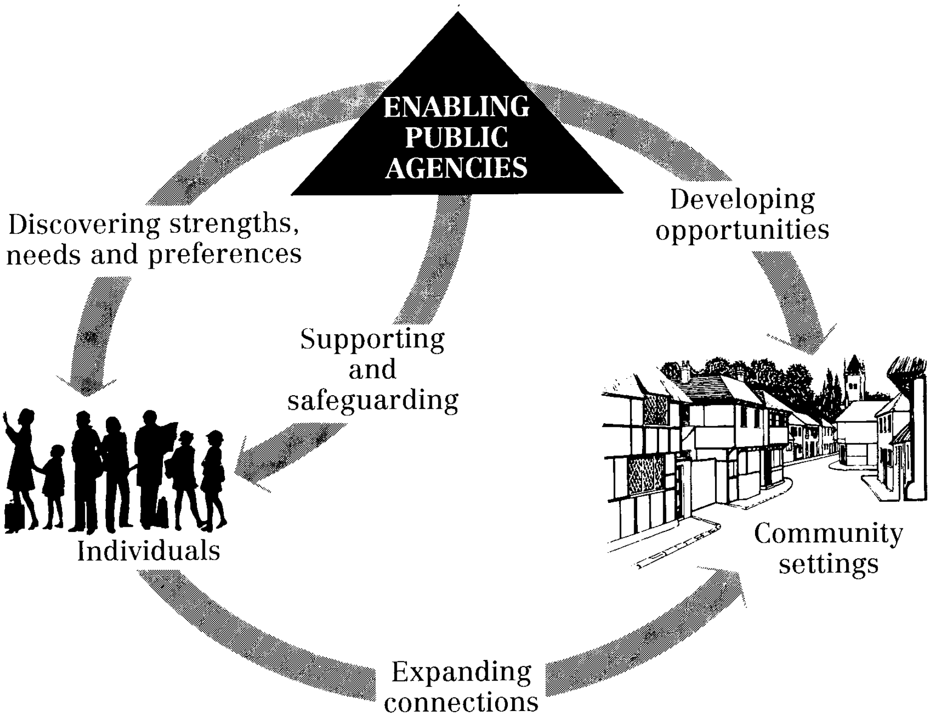
> 'in the mainstream of life, living in ordinary houses, in ordinary streets, with the same range of choices as any citizen, and mixing as equals with the other, and mostly not handicapped members of their own community'.

The design guidance in this first report focussed on residential services, but subsequent publications applied the same principles to vocational services; the importance of friendship networks; and constructive ways of meeting the additional special needs of people with challenging behaviour.

Desired outcomes

This initiative was distinctive, both in its primary focus on the *outcomes* to be achieved in people's lives and in its concern with *community integration.* At that time, much of the debate about service provision was about particular facilities, professional inputs

Figure 1 **Tasks for public services in promoting an ordinary life**



or agency responsibilities. *An ordinary life* saw the tasks for public services centring on helping people towards a desirable personal future. This meant linking help that promoted valued experiences with efforts to develop opportunities for participation in neighbourhood and other networks (Figure 1 following O'Brien and Lyle, 1987).

Section 3.2 presents a more detailed picture of what this involves, but a very useful framework for identifying positive outcomes is summarised in Figure 2 (based on Welsh Office, 1988). Agency success in promoting these outcomes means helping individuals with the support they need. In addition – and critically – it involves helping the community itself to become more inclusive. This means supporting family and friends who care; enabling mainstream schools to serve all local children; opening up employment opportunities; and encouraging leisure facilities and informal associations to welcome people with disabilities.

These ideas have been taken up in a wide range of local initiatives, through the efforts of many energetic people locally. As a result,

Figure 2 **Positive outcomes in people's lives**

Outcomes for people	Home life	Education/occupation	Leisure pursuits
Participating in the community	Growing up in families. Living in ordinary houses	Learning and working alongside other people	Using public leisure opportunities with others
Increasing competence	Gaining social and domestic skills	Gaining education and work skills	Gaining interests and participation skills
Exercising individual choice	Receiving opportunities and support for everyday decisions	Choosing among valued day-time activities	Expressing personal interests in leisure pursuits
Gaining self-esteem	Having personal space and supporting a positive image	Having opportunities to share and contribute	Enjoying life with others
Sustaining and widening friendships	Offering continuity in personal relationships and neighbourly links	Providing opportunities for developing varied friendships	Expressing and extending friendships in leisure activities

the component parts of the comprehensive opportunities and services of the future are becoming increasingly visible:

- They are there in family support services for children and in some examples of integrated education.
- They are there in the ordinary housing schemes including an increasing number which provide support for people with the most severe disabilities.
- They are there in the opportunities some people are finding for adult education and real jobs.
- They are there in increasing support for leisure activities that other people enjoy.
- And most importantly, they are there in an increasing emphasis on the importance of relationships, expressed for example in informal circles of support where ordinary people link up with an individual who may be at risk of serious disadvantage.

The success of these initiatives provides the basis for a bold vision of community integration for all people with learning disabilities as the target of public policy in the 1990s.

Progress and prospects

Currently, however, this is an optimistic vision. At the start of the new decade, the national transformation of opportunities and services is still at an early stage. Even some of the pioneer small-scale community-based services have themselves been limited – notably, in the extent to which they have sought to encourage choice for people with learning disabilities and widen their participation with non-disabled people in community activities. Some of the best have remained insecure in the absence of strong backing at senior levels in the relevant public agencies. In others, good support for people in one sphere – for example, at home – has not been complemented in others – for example, jobs. And continuity in relationships has often been undermined by rapid staff turnover.

Turning from the nature of services to their availability, there has been a gradual expansion of provision throughout the age range, from more intensive learning opportunities and support for the families of young children through to significant growth in day services for adults.

In the 1980s, the *Education Act* 1981 gave further impetus to appropriate individual assessment and curriculum development. The 'Care in the Community' arrangements and social security funding promoted new patterns of residential provision – with particular impact on the contraction of NHS institutions. Most positively, the 'All Wales Mental Handicap Strategy' provided a model of central leadership for planned growth in community-based services.

However, as a series of recent studies have testified, it is probably the case that despite these years of effort, the majority of people and their carers have so far seen little change. The most detailed empirical evidence here comes from the disability survey conducted by the Office of Population Censuses and Surveys (1989). Other commentaries from the Audit Commission (1989), the National Development Team (1990; 1991) and the Independent Development Council for People with Mental Handicap (1990) all converge on the view that most authorities face a major challenge in making the demonstrated successes of innovative projects available to large numbers of people with similar needs in their local population.

Service priorities

The evidence of National Development Team (NDT) reports on local services across England suggests that current service needs include:

- **For children:** further efforts to provide individualised support and improve service coordination – particularly between education and other public services – and encourage integration into local communities, all in partnership with parents.
- **For young people and adults:** more attention to planning the transition for children to adult services and a major investment in widening opportunities for employment and other appropriate day activities.
- **For the estimated 60,000 adults with severe learning disabilities still living in the parental home and the 27,000 people remaining in NHS institutions:** the planning and provision of alternative homes.
- **Across these services:** a significant drive to improve quality and ensure that provision is properly responsive to the situation of black and ethnic minority groups.

Moreover, far from moving forward on these tasks, the same reports suggest that the changing policy and resource context may now be putting at risk the modest rate of progress in the 1980s.

Constraints and opportunities

In effect, much of current social policy provides an unpromising backdrop for local initiatives. Particular problem areas include the failure to prioritise services for people with learning disabilities by central government; delay in implementing the *Caring for People* proposals; pressures on local government arising from the community charge legislation; upheaval in the NHS; educational reforms which may work against the interests of children with special needs; decline in the availability of low cost housing; and the continuing dependence of many people and their families on inadequate social security benefits.

At the same time, there are features of national policy – particularly *the Children Act,* 1989 and the *NHS and Community Care Act,* 1990 – which offer new opportunities, providing public authorities can organise to exploit them. Fresh thinking about the enabling role of public agencies; an emphasis on planning to meet population need; separation of planning and purchasing from provision; the focus on individually-tailored services; and growing interest in quality assurance could all be put to work in ensuring effective use of the limited resources available. Again, however, these system changes themselves constitute a major task for the public authorities, with implications also for independent service providers and voluntary agencies.

Dimensions of change

In summary, local and health authorities now face an inter-related set of changes in the substance, scale and systems for service provision which truly amount to a major *strategic* challenge (See Figure 3). Important dimensions of this challenge include:

- the shift away from defining services in terms of what is provided (the 'inputs') to a focus on the lives of people with learning disabilities and how the quality of their experiences can be safeguarded (the 'outcomes');

- the move from planning provision for categories or groups of people towards the design of supports around individuals;
- the transition from segregated services towards the use of mainstream opportunities and fuller integration in community life;
- the expansion of agency attention from users and unpaid carers alone towards promotion of wider opportunities for community participation;
- the shift in emphasis at the leading edge of service development from innovative projects towards the qualitatively different tasks of reproducing comprehensive services to the local population in ways which respond to race, gender and other differences;
- the redefinition of agency responsibilities, including for leadership, within a necessarily multi-agency pattern of local provision;
- the shift from bureaucratic administration of services towards a view of public authorities as enabling agencies in a pluralist pattern of provision, with consequent changes in planning, finance and management systems;
- the parallel shift in public service culture away from the tradition of 'providers and receivers' towards a partnership model in which paid staff, people with learning disabilities, their families and the wider public are all active participants in creating more integrated communities.

All this represents a major challenge in the current resource climate, with clear risks of disappointment where local initiatives address only part of this agenda. The experience of the authorities with whom the King's Fund has worked over the last four years provides important lessons for the local strategies most likely to contribute to achieving large-scale change.

Figure 3 **Dimensions of strategic change**

Traditional provision		Enabling integration
Inputs	⇨	Outcomes
Groups	⇨	Individuals
Segregation	⇨	Integration
Providing services	⇨	Expanding community
Projects	⇨	Population planning
Dividing clients	⇨	Multi-agency coordination
Bureaucratic provision	⇨	Enabling pluralism
Paternalistic culture	⇨	Partnership

2.2 Building local strategies

Reviewing this variety of local experience, we have concluded that there are no short cuts to securing and sustaining better lives for vulnerable people. Promoting community integration is necessarily a lengthy, problematic, sometimes frustrating but creative and rewarding process which requires the very best of collective local intelligence and commitment, while keeping people humble about the state of the art and the extent of achievements.

Nevertheless it *is* possible to draw from this wealth of experience a picture of the elements which seem necessary to maximise the success of public sector initiatives within the resources which can be generated. (Figure 4). What follows enlarges on this picture to offer a *diagnostic guide* for assessing the strengths and weaknesses in particular local strategies and thereby identifying priorities for managerial attention.

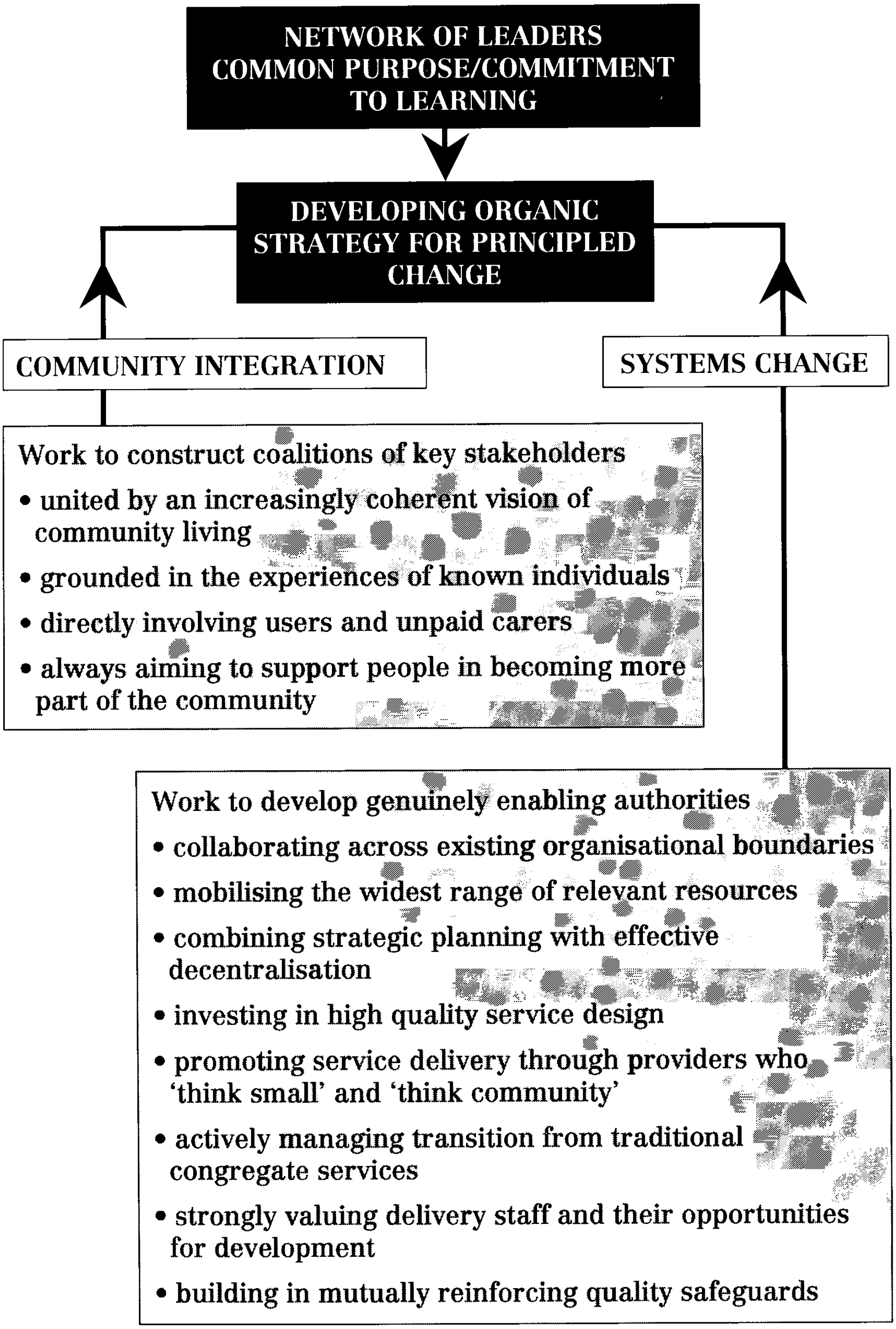
Purposeful leadership

There are many points here, but *one* requirement seems fundamental. It is the development of a network of leaders inside and outside the main public authorities who share a common sense of purpose; a thoughtful approach to mobilising action; and a commitment to learning from both successes and disappointments as change proceeds. Using – at least implicitly – a framework like that suggested in Figure 4, successful leadership at the strategic level appears to require a continuous process of diagnosis, development and review designed to maximise progress towards positive outcomes.

In this respect it corresponds with recent thinking about strategic management in other organisations. This process is also very challenging. It requires a sophisticated understanding of the different 'pieces of the puzzle' which go together to achieve change in human services, and a continuing willingness – through keeping in touch with the real experiences of vulnerable people – to examine whether the 'picture' could be improved by reshaping one or more of these pieces.

Given this approach, the King's Fund programme has also been able to identify which pieces of the puzzle it seems most important to

Figure 4 **Building effective local strategies**



NETWORK OF LEADERS COMMON PURPOSE/COMMITMENT TO LEARNING

DEVELOPING ORGANIC STRATEGY FOR PRINCIPLED CHANGE

COMMUNITY INTEGRATION

SYSTEMS CHANGE

Work to construct coalitions of key stakeholders

- united by an increasingly coherent vision of community living
- grounded in the experiences of known individuals
- directly involving users and unpaid carers
- always aiming to support people in becoming more part of the community

Work to develop genuinely enabling authorities

- collaborating across existing organisational boundaries
- mobilising the widest range of relevant resources
- combining strategic planning with effective decentralisation
- investing in high quality service design
- promoting service delivery through providers who 'think small' and 'think community'
- actively managing transition from traditional congregate services
- strongly valuing delivery staff and their opportunities for development
- building in mutually reinforcing quality safeguards

concentrate on in building effective local strategies. There are two sets of these, one concerned with community integration and one with systems change.

Coalitions for progress

Achieving principled change is essentially a political process. People with leadership opportunities inside and outside the public agencies have had to work – sometimes over several years – to construct coalitions among the key stakeholders. These are needed to exercise real influence on local decisions about policy and resources. For example, in the North West of England, a tireless network of professional leaders – increasingly working with users, parents and community interests – has persevered over a decade to mould the whole region's strategy. Initially their work focussed on gaining wide support for the principles of 'an ordinary life' and ensuring these were built into public sector planning. More recently, they have had to struggle both to maintain priority for these plans and to ensure that the commitment to quality is central to a wide variety of service delivery arrangements.

Starting from individual experiences

These coalitions have organised around an increasingly coherent vision of what life as part of the community should mean for people with learning disabilities. This vision is sensitive to people's position in the life cycle and to different cultural expectations. In all the places where the King's Fund has been working – and most notably in Wales – there has been growing understanding of the support which needs to be available to enable people to grow up in families, go to ordinary schools, live in their own homes, hold proper jobs and develop more friendships.

The single most important stimulus to creating this vision – and a key feature of new approaches to tailoring services around individuals – has been the willingness to start from the experiences of people with learning disabilities in seeking to shape more positive opportunities and supports – in short, to 'put people first'.

Expressed more technically, imaginative approaches to personal futures planning are needed in which people with learning disabilities, key members of their informal networks, and relevant staff share in assessing individual requirements and identifying opportunities for progress. Where this is starting to be done well, for example in the Andover and Wakefield case management projects, it provides an important vehicle for helping people gain more control over their lives and build bridges to the wider community. Where this process is gaining momentum, it also offers a powerful stimulus for gradually remodelling the whole pattern of inappropriate existing provision.

The views of service users must be at the centre of these individual plans. It is also clear, not least from the growing strength of the self-advocacy movement, that it is important to involve people in shaping these wider changes directly. For example, in Birmingham and Grimsby, public agencies are beginning to open up their bureaucracies to the views of users and unpaid carers through a variety of participative arrangements.

The more successful agencies are starting to think carefully about the meaning of community to people with learning disabilities. These agencies have begun to appreciate the different ways in which support might be offered so as to strengthen community integration. They have begun to design services which enable people to live fuller lives without becoming wholly incorporated into the world of paid providers.

Changing systems

With these requirements in mind, people in the places which are making most progress have also begun to learn how to change the public agencies responsible for planning and funding these services. Elements of the new approaches which seem to be necessary are visible in places as different as Camden and Kent. In trying to understand how best to make use of recent legislation, lessons can also be drawn from more distant experience, for example in Michigan and Massachusetts.

In most places there is still a long way to go, but experience suggests that the idea of public agencies acting as enabling authorities can be a positive one, provided that enabling is understood in its true sense – of using agencies' democratic authority and organisational power to work for local communities which include people with learning disabilities as full members. Given the structure of public services, this means collaborative efforts across local and health authorities. Taken together, for example, the public authorities are the major employers in many communities. As places like Calderdale and Lambeth have shown, this power can be used to ensure that more people with disabilities get proper jobs.

A key task of leadership in the enabling authorities is to use their political skills to attract the resources necessary to provide opportunities and services consistent with agreed principles. Again this requires multi-sectoral initiatives. The pursuit of community integration requires local agencies to mobilise the widest range of relevant resources, not just the cash tied up in specialist services but also contributions from housing, leisure, education and employment creation, in order to widen the opportunities and support which are made available. People also need welfare rights advice in order to achieve their full entitlement to a personal income.

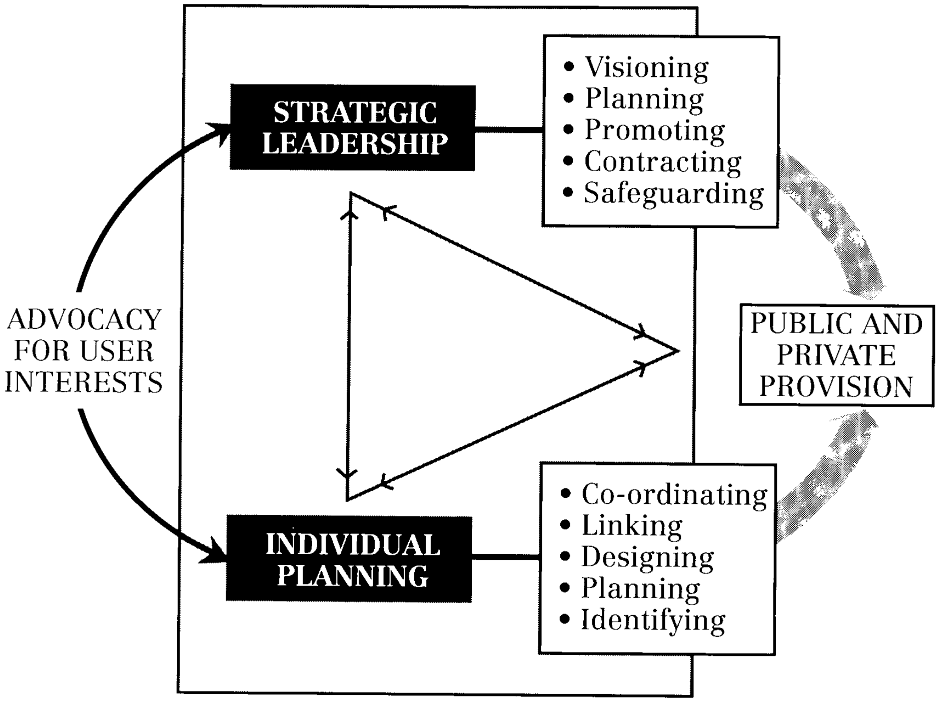
At the same time, experience has shown that the resources already invested in services for people with learning disabilities are often poorly employed. Through these approaches, people already using traditional services, for example, residential care, can be offered much better quality support with on average somewhat greater costs spread among more contributors. Equally, however, authorities planning to meet population requirements are recognising considerable unmet need and therefore further demands on resources. Leadership is also important in identifying priorities, setting decent standards and confronting the tensions that these policies necessarily involve.

Decentralisation

In developing this enabling authority role, members and managers need to think carefully about how best to combine their responsibilities for strategic leadership – for example in determining priorities and developing a corporate vision – with the decentralisation necessary to ensure that services are designed and money spent close to users.

North American experience suggests that the key requirement is skilful management of the triangular relationship between strategic planning, the purchase and provision of services, and arrangements for tailoring opportunities to meet individual needs (represented in Figure 5). This in turn implies significant changes in the ways public authorities work; new skills in planning, contracting and care management; and significant investment in relevant financial and information systems.

Figure 5 **Key management functions of the enabling public authority**



Service development

In making these arrangements work, it is clear that the development of good quality services is both technically and managerially demanding. The best projects providing ordinary housing options for people with severe disabilities in Andover, Bristol and Cardiff, and also the more recent supported employment projects in places like Hammersmith and Sheffield demonstrate this. The public authorities need therefore to continue their investment in staff with the necessary skills in service design and development, who are able to draw on what has been learnt about the factors which determine quality from the most successful innovations of the past decade. This is particularly important if people with more complex needs are to be offered genuine choices among desirable alternatives.

It is also clear – for example from the experience of voluntary organisations like Barnardos, CSMH in Camden and Antur Waunfahr in North Wales – that providing agencies need both to 'think small' and 'think community' if they are to offer services which are as close as possible to the normal patterns of life which most people take for granted.

Managing transition

Given the challenges described at the outset, this emphasis on the development of community-based services still needs to be complemented by major investment in properly managing the transition from out-dated forms of segregated provision. A significant part of the resources – both human and financial – required to support community living, enable people to participate in mainstream education and sustain proper employment are currently locked in residential institutions, special schools and training centres. Achieving change requires authorities to pursue policies which provide clear direction to managers at the same time as they offer financial incentives for change and allow the 'bridging' costs of transition to be met.

As experience with the contraction and closure of NHS institutions demonstrates, change also requires high quality management for traditional services during the period of transition to encourage staff support for change, maintain standards and ensure that client relocation is planned individually, with the full participation of people and their relatives.

Valuing Staff

All these things are likely to be more meaningful where employing authorities demonstrate that they value the contribution of their staff and take seriously their needs for relevant training opportunities. On the one hand this implies developing personnel policies and negotiating with staff interests to produce a positive climate for change within which individuals can see that their employment prospects are being properly addressed. It also requires a longer term approach to workforce planning which recognises both new service needs and changes in labour markets.

On the other hand it implies well-designed investment in developing staff motivation and skills: recognising that their performance is critical to success in delivering better services. As experience in the

South East Thames region shows, staff training cannot be a substitute for good service design. Rather, these two activities need to be integrated in 'training for service development' initiatives, addressed to priority issues on the change agenda.

Pursuing quality

Taken together, the preceding points constitute the essential requirements for ensuring the quality of local services. Authorities must aim to develop a 'quality culture' in which concern with the impact of all decisions on people's lives is intrinsic to policy-making, planning, financing, contracting, managing and delivering services.

In addition to these managerial requirements, however, experience suggests that a multi-faceted set of further quality safeguards are necessary, particularly to protect the interests of the most vulnerable people. Initiatives are required at different levels in the purchasing and providing agencies, and also from different perspectives. Internally, for example, 'quality action groups' provide a useful vehicle for promoting participation in performance review. Externally, it is important that users, relatives and advocates have a variety of ways of influencing provision. And there is also likely to be merit in some forms of independent inspection and evaluation.

Last but not least on this list, agencies need a commitment to learning from experience as new approaches are introduced. Significant developments often need to be modelled on a small scale first, in order to demonstrate their effectiveness (or the contrary) and to identify other changes – for example, in organisational structures and staff skills – needed if they are to be implemented more widely.

Most importantly, in places where the most progress is being made, local leaders are continually working to weave these fifteen strands of activity together into a rope strong enough to mobilise and sustain strategic change.

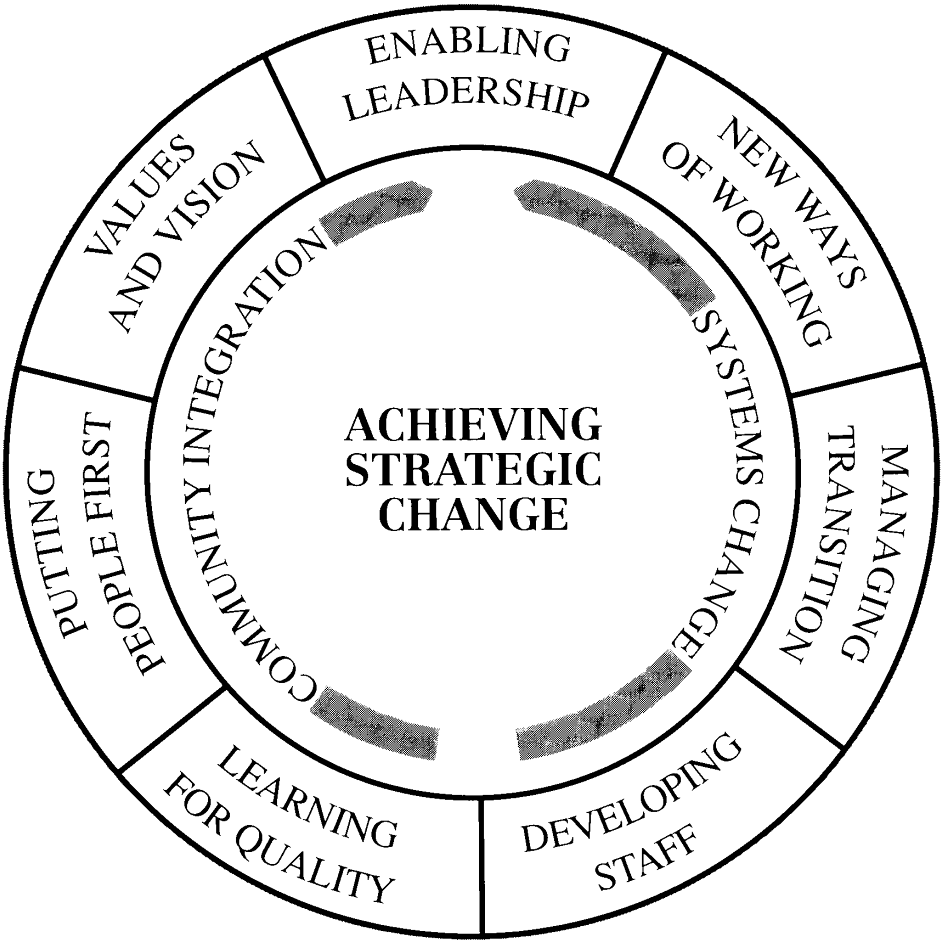
Readers using this overview as a diagnostic guide for reviewing particular local strategies are likely to identify significant local strengths on which to build and also gaps and discontinuities which need to be addressed in promoting further progress. Typically, it will be important to think strategically but to act selectively by focusing managerial and other effort on priority issues for attention. Next steps will therefore vary according to the current situation and to opportunities which can be created in different places. In deciding priorities, the experience of the King's Fund programme suggests three further pointers:

- **Work to ensure leadership is shared**
  The complexity and fragility of strategic change initiatives can best be handled where a network of concerned people is sharing the challenge of shaping and sustaining effective action.
- **Start from 'ends' not 'means'**
  Despite the pressures – not least from the weight of central guidance following recent legislation – to focus attention inside the bureaucracies on the mechanics of new planning and delivery arrangements, it is vital that change starts from the experiences of people needing services and a strong sense of the opportunities and supports which would make a positive difference in their lives.
- **Plan the 'macro' with lessons from the 'micro'**
  Action at the periphery – where providers and users of services meet – is critical for success. Large-scale change must be grounded in and planned to reinforce what can be learnt from small-scale innovations which work.

Against the background of this diagnosis and decision guide, Section Three brings issues from the overview together to describe in more detail seven key elements for building effective local strategies, each illustrated with examples from recent experience.

3

Seven key elements in successful local strategies



3.1 Leading the enabling public authorities

As the preceding overview suggests, effective leadership is the key to mobilising the changes needed to achieve large-scale improvements in the opportunities available to people with learning disabilities. Doing so means combining a new understanding of the enabling functions of public authorities with a positive vision of community integration. The *content* of this vision is considered in section 3.2. This Section examines the nature of this enabling function and identifies what is being learnt across the country about appropriate leadership within it.

Local authorities are the basic unit of democratic organisation in Britain. As such, they need to be concerned with the overall welfare of their population, as well as with executing their explicit statutory duties. Increasingly, this over-arching responsibility is being reflected in a new interpretation of the main function of local authorities as being to *enable* local communities to tackle the problems they face.

There are divergent strands in the origin of this concept and its political interpretation, but a positive view of enabling implies at least three elements:

- genuine attention by public authorities to learning from local people about their concerns;
- willingness to work with and through other agencies, including organised groups of citizens, both to promote action on these concerns and to widen the choice of responses available;
- a broad interest in strengthening the capacity of local communities to meet future challenges.

Accordingly, the successful enabling authority needs to develop ways of identifying locally important issues to inform its strategic planning. It needs to develop ways of listening carefully to public views and of involving disadvantaged groups. It also needs to ensure that its own services are properly responsive to user preferences.

At the same time, enabling authorities need to stimulate, shape and monitor the contribution of other agencies. Tactics they can use to do this include inter-agency partnerships; purchase of service contracting; support to voluntary organisations and general public relations activities, as well as the exercise of regulatory powers; and inspection procedures.

Enabling authorities also need to use their planning, educational, employment creation and community development functions to reinforce the more informal arrangements with which families, neighbourhood groups and networks typically respond to local problems.

Despite the different accountability structures of the health service, some of these approaches are becoming relevant to district health authorities and family health services authorities as the *NHS and Community Care Act* 1990 is implemented. In particular, the separation of service purchase from its provision and the introduction of funding based on the needs of the local population suggest the development of an 'enabling' role for health authorities as well. This is bolstered by a growing interest in defining objectives in outcome terms – for example, in moves to maximise 'health gain' for resident populations within available resources. In practice – and like local authorities – health authorities have a duty to address the needs and wishes of their resident population; to work through a more diverse 'internal market' of provision to meet these needs and to collaborate with other agencies in public health strategies designed to promote health and prevent illness as well as provide treatment.

These broad developments are relevant to people with learning disabilities and their families. Indeed, the contrast between traditional provision for people with learning disabilities – typified by a single agency directly providing '24 hour care' in ways which segregated them from other people – and the new philosophies of community living, which depend for their success on opening up opportunities and linking the contribution of many public, private and voluntary agencies, make services for these people a test case for the enabling role.

Looking across the authorities with which the King's Fund programme has worked, it is clear that this challenge puts a premium both on the capacity of leadership to 'make things happen' and on management to ensure that this effort is used to maximum effect. Members of public authorities and their senior managers have the authority needed for exercising this strategic leadership. However, our examples suggest that the momentum for change does not always start at the 'top'. In any case, effective leaders are those who stimulate and support others to exercise leadership.

Within public authorities, successful leader/managers appear good at working with others to link together the two continuing cycles of activity represented in Figure 6.

As leaders, they need to:

- build networks with others seeking positive change in community opportunities and services;
- develop a diagnosis of the current situation of users;
- create and promulgate a vision of more desirable futures for people;
- identify and build support for the actions required to make a difference; and
- ensure that serious efforts are made to learn from experience.

As senior managers they:

- use this cycle of diagnosis, development and review to establish more formal goals and policies for their authorities;
- make plans with other relevant agencies;
- seek political support for the necessary allocation of resources;
- use pilot projects and other exploratory work to plan the phasing of larger-scale implementation; and
- identify the personnel, organisational and systems changes required to support new ways of working.

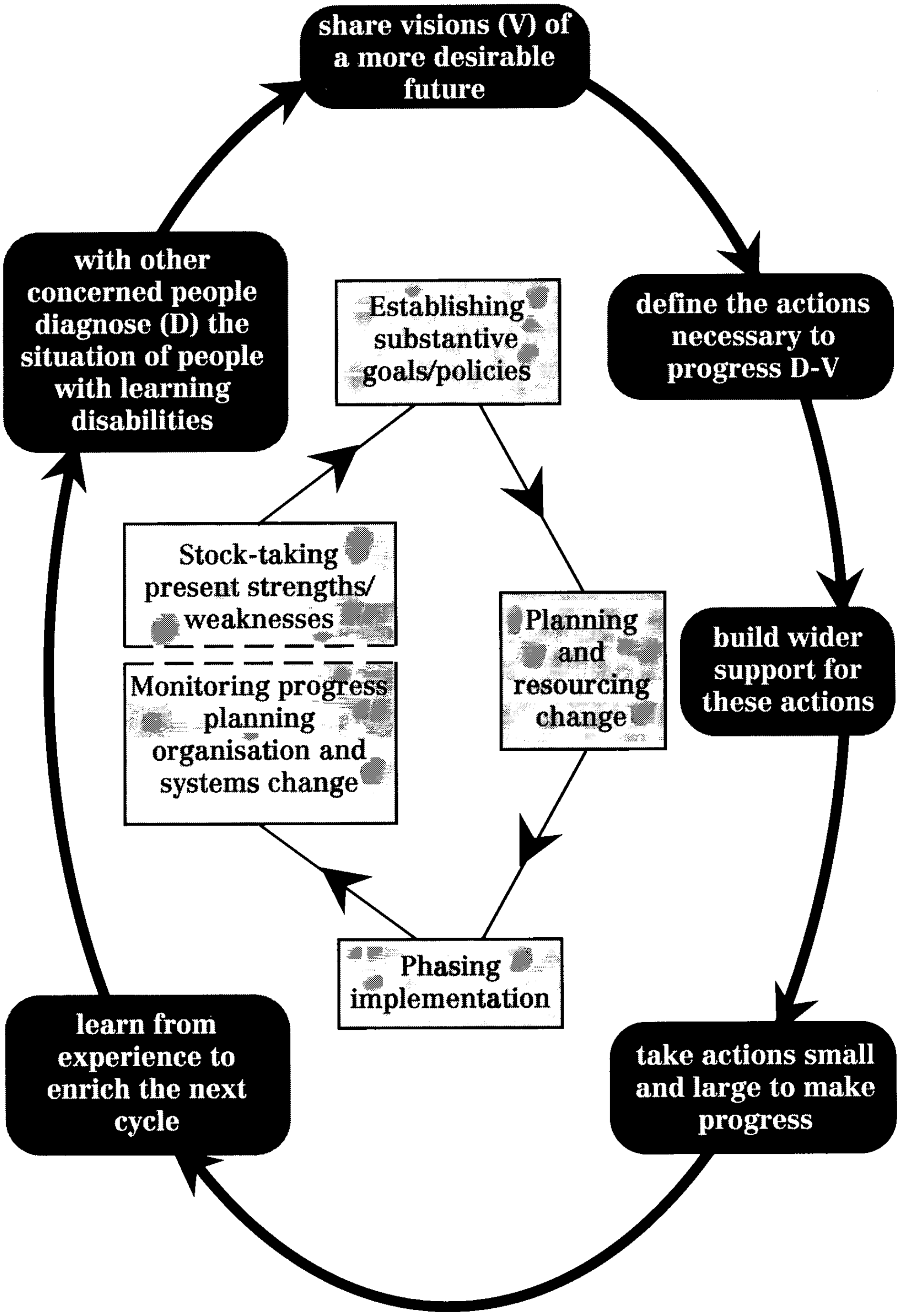
In all of this, leader-managers look outside their agencies to address – and where possible, influence – opportunities and constraints arising in the wider environment. These may come from national policies, the changing contributions of other agencies or from pressures generated by changing public expectations.

What does this mean in practice, particularly for promoting improvements in opportunities and services for people with learning disabilities?

Orchestrating the new vision

First and foremost, key people in successful authorities have recognised that leadership is required to orchestrate a new vision of the opportunities and support which should be available to people with

Figure 6 The continuing leadership/management cycle



learning disabilities. Critically, this needs to inspire and energise others. In Wales, for example, government itself has been the lead agency for the 'All Wales Mental Handicap Strategy' for the past eight years. Here, the political authority of Ministers has been used to build support for principled change. The centre has also used its administrative authority to devise policies, incentives and monitoring tools to keep the Strategy on course.

On a smaller scale, Lewisham and North Southwark Health Authority has established new directions for services through a detailed planning and consultation exercise. This approach was distinctive in offering a coherent alternative to past incrementalism. In Somerset, good relationships among a small core of senior managers and influential professional staff enabled the key agencies to work to the same change agenda over a period of years.

In places where there is a shared vision, health and social services authorities are now well-placed to use the new requirement to separate purchasing from providing to improve the opportunities available to people with learning disabilities locally. The importance of positive leadership in this new context is suggested in Box 1. This describes the large-scale change achieved by a public agency in North America, which works largely through purchase-of-service contracting. Here, the willingness of senior managers to demonstrate a direct interest in the experiences of vulnerable people and an overriding concern with the impact of all agency decisions on their lives was essential to positive change.

A bias to action

A second important feature of successful leadership is a bias to action. This involves a willingness to test out elements of the vision – often initially on a small scale – to learn how best to make more substantial progress. This approach has been reflected both in widespread piloting of innovative approaches to service provision – for example, the spread of home teaching for young children on the Portage model and the development of staffed housing schemes – and the development of new ways of working. Local initiatives to develop systematic individual programme planning provide one example of this.

As well as offering more concrete demonstrations of the vision, these initiatives also allow managers to correct for un-

BOX 1 Leadership lessons from MORC

The Macomb-Oakland Regional Center (MORC) is a regional agency of the State of Michigan Department of Mental Health – responsible for residential and treatment services to children and adults with severe learning disabilities in a two-County population of 1.4 million people. Working closely with other community services, and itself acting principally as the purchasing agency for services provided through an extensive not-for-profit sector, MORC has succeeded over fifteen years in developing community living options (mainly foster placements and staffed housing) for 2,000 people who were, or would otherwise have been, institutionalised.

MORC's Director throughout this period has been Gerald Provencale. He argues that the most important factor in this success has been the agency's commitment to a vision of community living for all people with disabilities and an orientation which combines 'urgency', 'ownership' and 'action'.

> *'It has been our experience, not just our philosophy, that where people (with learning disabilities) move down your and my street, they have the opportunity, where we offer proper support, to participate in the community, to grow, and to live fuller and richer lives.*
>
> *Achieving this on a large scale has required from all of us a sense of urgency about their plight, the way in which their time is wasted and the ordinary pleasures of life denied them. It has required us to stop blaming others for lack of progress and instead to own the problems ourselves. It has required from all of us a commitment to take action this day to help people (with learning disabilities) make real gains.'*

BOX 1 *continued*

Visitors to MORC are typically impressed with the way these views permeate the whole culture of the agency, not just its senior staff but also its case managers, its professional specialists and many of the small provider agencies which MORC staff have helped to establish. Continuity in the top management team as MORC has grown from a small to a large state agency has been one important influence here, as has their clarity about what the agency is in business to do.

This positive culture is reinforced by the way MORC is led. During growth, the organisation structure has remained simple, flat and informal – top people are readily available to other staff and to consumer representatives. Senior people stay 'close to the customers' and model the commitment to keeping in touch with what is happening in the lives of particular individuals.

Staff at all levels are highly valued and encouraged to use their personal initiative; successes are publicly celebrated; mistakes are accepted as an opportunity to learn; and anyone can initiate a problem-solving meeting outside the usual channels if there is concern about clients getting a poor deal. At the same time this flexibility is complemented by an extensive array of explicit quality safeguards which underline the agency's primary commitment to achieving better lives for people with learning disabilities.

Source: Provencale, 1987; Winkler, 1991.

anticipated outcomes, clarify design details and identify the changes needed if similar approaches are to be implemented on a larger scale. This in turn requires leaders who promote a climate in which successes are shared and people are able to face up honestly to disappointments.

Widening and maintaining support

The third key function of leadership is to gain and maintain support for new approaches and their implementation. This involves building an authoritative mandate for change and gaining political commitment to its resource consequences. It also implies a commitment to the democratic process, which draws the public and relevant interest groups into dialogue. The way civil servants secured support for the All Wales Strategy provides one example here, as does the Birmingham Community Care Special Action Project in which leading councillors played a significant initiating role and key officers encouraged pressures from external advocacy groups.

The Birmingham Project is also an example of efforts to build support 'sideways' by working across departmental and agency boundaries – in this case by involving chief officers of different departments of the City Council and district health authorities in a joint steering group for developing community care. In practice, the enabling function of public authorities, getting people with learning disabilities access to 'mainstream' opportunities for education, work and leisure, and the need to mobilise the widest range of relevant resources all require this kind of collaboration. This is recognised in some regional strategies which have brought together the NHS and social services departments in formal coalitions of the kind established in the North West and South West of England. It is also explicit in some local collaborative arrangements like those in Camden – where health and local authorities consciously sought to develop a tri-partite service delivery partnership with a major voluntary organisation – and Southwark – where this kind of partnership has been developed through a formal consortium, which includes a housing association.

These arrangements have required leadership to build positive relationships, generate shared objectives and identify areas of interdependence which make inter-agency collaboration an opportunity for mutual gain. They have also required effective management to create simple machinery for joint planning; focus effort productively; and provide incentives for success.

Also essential (as we discuss in more detail in 3.3) are leadership activities which reach outside the bureaucracies to link up with users and unpaid carers; seek coalitions with the leadership of advocacy organisations; and actively work to reduce barriers to people's participation in community life.

Mobilising staff support

Fourthly, leadership has a critical role in mobilising staff support for change while working to create the conditions in which a wide variety of staff at all levels can themselves be innovators. Box 2 provides an example drawn from twenty years of effort in the North West of England. In this and other examples, senior managers have combined clarity of purpose with the sensitivity to recognise the tension between positive aspirations and the current situation for users of services. They have accepted the need to face up to doubts, encourage constructive debate and provide support to people in working through conflicts. They have also sought to find creative ways of working which reduce the likelihood of mechanistic responses by staff or personal 'burnout'. These include exchange visits, search conferences and participation events.

Successful leaders appreciate that the development of good quality opportunities and services for people with learning disabilities requires a wide variety of action at different levels in public authorities and across provider agencies. It is particularly important at 'street-level' where staff and people with learning disabilities meet.

In the North West, the importance of street-level leadership has been demonstrated by the charge nurses who pioneered shared living arrangements with Calderstones residents; the day services officers who left their Adult Training Centres to partner individuals in finding more integrated day-time pursuits; and the parents who developed voluntary organisations to provide proper homes for their adult children to move into. Senior managers can demonstrate that they value such initiatives by listening widely to grass roots contributions and backing people willing to give new ideas a try.

Another large-scale example of this approach is provided by the way the South East Thames region achieved the closure of Darenth

BOX 2 Networking for change in the North West

Among English regions over the past decade, the most sustained progress towards community-based services for people with learning disabilities has been achieved through the partnership of health authorities and social services departments in the North West. Many strands of leadership have contributed to this progress but perhaps most important has been the contribution of key NHS staff, building on initiatives which go back at least 20 years. Indeed it is possible to identify two ten-year cycles of change, the second of which has amplified the processes set in train during the first.

During the 1970s at Calderstones – then still a huge institution with nearly 2,000 beds – new medical and nursing leadership worked to create a dynamism for change 'from within' with a focus on increasing the dignity of individual residents. Senior managers set the direction (for example, every nursing job description included 'encouraging the recognition of the resident as an individual') but also facilitated grass roots initiative:

- by encouraging multi-professional groups to go away to see the best of what was being achieved elsewhere;
- by backing pilot projects (eg. group homes and life-sharing arrangements) which demonstrated new possibilities;
- by seeking to learn from these initiatives; and
- by promoting widespread debate about the way forward.

The significant achievements through these efforts and their wider recognition meant that those centrally involved, both at senior levels and in particular projects, were well placed to influence the second and larger-scale cycle of change in the 1980s.

In this second cycle, local managers and influential professional staff were able to work – initially

BOX 2 *continued*

with officers of the Regional Health Authority, later extended to representatives of local authorities and parent interests – to establish a strong regional policy framework based on 'an ordinary life' principles. From 'above' therefore, local agencies were offered both a clear vision, detailed guidance on implementation and financial incentives for change. Learning from the previous cycle, there was also extensive investment in 'lateral' and 'bottom up' initiatives:

- by linking up with leading edge developments elsewhere to clarify and contribute to national thinking (eg. on the importance of employment opportunities, the growth of citizen advocacy);
- by widening the range of innovative development projects;
- by encouraging internal and external quality review; and
- by fostering high quality training opportunities which brought people together across the region.

Indeed key people involved throughout this period explicitly recognised the importance of Emery's observation that 'Dispersed but cohesive networks represent the strongest and most powerful infrastructure for both effective implementation of innovation and continued diffusion'.

In the 1990s, this extensive leadership network is now facing up to the challenge of maintaining the momentum for change while public services are restructured and working through the conflicts (for example, with parent groups still favouring segregated services) which are necessarily associated with any radical transformation in provision.

Source: Gathercole et al, 1988; NWRHA, 1990.

Park Hospital (described further in Box 8). Here, traditional 'top down' planning was replaced by explicit strategic leadership which provided the framework for decentralised implementation. This was reinforced by positive incentives for change.

Similarly, in preparing for the implementation of *Caring For People*, Humberside's senior social services managers have tried to provide a clear agenda for change. To do so, they have broken down a complex programme into specific objectives and short-term action plans which have given structure to widespread participation by middle level staff in shaping their new department – and at the same time as developing their own capacity for leading subsequent implementation. A further lesson from this experience is that leadership has an important function as a 'container' for the anxieties raised both by environmental uncertainties – in particular, the national postponement of new funding proposals – and internal change – for example, new role definitions. This helps people to maintain a clear sense of direction.

Making change stick

Fifthly, effective leadership is about 'making change stick'.

Innovation is rarely achieved once-and-for-all: it has to be maintained over time in the face of many pressures which can undermine the original goals. It also needs to be renewed in the light of further opportunities and experiences. On a larger scale, as all the preceding examples suggest, sustained change requires skilled advocacy and careful efforts to 'anchor' the vision in agreements between public authorities. These must themselves be reflected in the wider policies, procedures, reward systems and accountability arrangements of these authorities and – ultimately – in the culture of the whole service-producing enterprise. We examine these wider requirements further in Section 3.4.

3.2 From values to vision

All services, and the policies that underpin them, are shaped by views about the kind of lives which should be offered to people with learning disabilities. This process is often an implicit one, but it is always influenced by wider societal values.

Many of the services designed for people with learning disabilities continue to reflect their stigmatised position within Britain. They concentrate on segregating people into devalued settings separate from the mainstream of community life. These include 'special' schools and colleges, and separate accommodation, transport, workplaces, day centres, clubs and activities. Within these settings – many of which are designed for large groups – many services continue to pay insufficient attention to the strengths, preferences and hopes of the individual people that use them and their families.

Given these problems, many people continue to experience services that do little to create worthwhile opportunities for living and working in the community.

A related problem is their frequent failure to provide continuity of support. All too often, people with learning disabilities and their families find services poor at working across the boundaries between social services, education, health, housing and income support. These weaknesses are often magnified at key transition points – for example, as young adults leave school. At a day to day level, too, many find that frequent staff changes and rigid procedures mean that services do not provide the kind of reliable, knowledgable help that they need.

Starting with principles

In challenging this inheritance, many of the local initiatives which have aimed to promote better quality lives for people with learning disabilities and their families have begun by clarifying a set of explicit values to underpin service delivery. Where this has been most effective, people with a major interest in services – managers, professionals, care staff, families and people with learning disabilities themselves – have worked together to build agreement around their values, and have found a way to express them as principles to guide service design and development. A variety of techniques can be helpful here – search conferences, workshops structured around shared analysis of desirable outcomes and participative approaches to personal futures planning.

The King's Fund's own 'an ordinary life' initiative began from the three fundamental principles that:

- people with learning disabilities have the same human value as anyone else, and the same human rights;
- living like others in the community is both a right and a need;
- services must recognise the individuality of people with learning disabilities.

These principles informed a wide variety of small-scale innovative projects and service developments. Increasingly, they have also been reflected in more extensive statements of principle, including the All Wales Strategy and the North Western Regional Health Authority's 'model district service'. More recently, they have been well expressed in the statement of philosophy and principles developed by the Association of Directors of Social Services (ADSS), which are reproduced in Box 3.

Working through values

Working out a set of values is not, of course, an end in itself. The process becomes most useful if the values – and their full implications – are considered at every stage of service design, development, delivery and monitoring across the full range of provision in a given locality. Agency managers need to get together with each other and with service users and carers as well as direct care staff if this is to be done effectively.

The ADSS statement provides a useful example of what this might involve. It systematically works through the implications of its basic service philosophy and principles for the provision of care, accommodation, daytime activity, leisure and specialist services for people with learning disabilities, as well as the financial arrangements and staff training needed to underpin them.

In all the authorities with which the King's Fund has been working, this principled approach has stimulated continuous reassessment of the capacity of people with learning disabilities for involvement in mainstream activities along with their contemporaries. It has also required health and local authorities to consider their contribution to 'opening up' a range of community-based opportunities for education, employment and leisure to people with disabilities.

As a direct result, over the 1980s the 'goal posts' for service delivery have shifted to reflect much more ambitious aims in terms of the quality of life people with learning disabilities should expect. At the same time, their ability to make a positive contribution to family and community life has become better understood.

Needs and expectations

Drawing on the best of what has been achieved in different places, the kinds of support that people with learning disabilities and their families need for community living are now much clearer.

When children with learning disabilities are young, they need the love, care, attention and security that family life is best at providing. As they grow up, they will need to move outside the family circle to learn from a wider set of adults and contemporaries both in formal education and outside it. When they leave school or college they will need a job – or some other worthwhile way of spending their time during the day – and enjoyable ways of passing time outside work or their usual daytime occupation.

In all these settings, people with learning disabilities will need opportunities to acquire skills. They will also need the chance to make choices about things that affect their lives. They will often need help to take advantage of these opportunities.

As grown-ups, they will need to develop a variety of relationships with family, partners, friends, workmates, neighbours and other people in the places where they live and spend their time. As they grow old, they will continue to need companionship and friendship from people who care about them.

People with learning disabilities will need general health care. Some people will also need specialist help from health professionals and others to cope better with different aspects of their disability – for example, with epilepsy or with behaviour that others find difficult to deal with.

The form that all these needs take will be shaped by the social, economic and cultural background of individual people with learning disabilities and their families. People from minority ethnic commu-

BOX 3 Service principles

Philosophy to guide the planning of future services

People with mental handicap/ learning difficulty are people first and mentally handicapped second.

- They and their families should be consulted about the type of services or help they need.
- They should be enabled to share in and contribute to community life, including family life.
- They should be given the extra help they need to achieve this.
- They should receive the least restrictive services possible.
- They have a right to be treated as individuals.
- They have the right to participate in decisions and choices affecting their lives.
- They should receive help that is designed to maximise their potential as individuals to the full.
- They should not be discriminated against or segregated from society as a result of age, sex, ethnic origin or severity of handicap.
- They should be accepted as valued members of the community and should not be withheld by their carers from contributing towards the general well being of society.
- Special consideration needs to be given to the needs of ethnic minority groups to ensure equal opportunities are achieved.

BOX 3 *continued*

Principles to underpin local comprehensive services for people with a mental handicap/ learning difficulty

People with a mental handicap/ learning difficulty are entitled to the same range and quality of services as are available to other citizens and in addition are entitled to services designed to meet their special needs.

- Services should be designed to enhance their development throughout their lives.
- Services should be provided on the basis of an inter-disciplinary and inter-agency assessment of need and consumers should be helped to participate in the assessment.
- Services should be reviewed annually and where necessary adjustments made in accordance with the changing needs of individuals through life from childhood to old age.
- Staff employed in services should apply their skills in the least restrictive environment possible and in the way most appropriate to the individual needs of people with a mental handicap/learning difficulty.
- Services should promote independence, and choice and risk taking should be seen as an aid to personal growth.
- The needs of people with a mental handicap/learning difficulty and their carers and families, which may be different, should have priority over organisational or administrative convenience.
- Services should be easily accessible and comprehensive.
- Arrangements need to be made to cover the special needs of ethnic minority groups to ensure that they are aware of the services available, and to ensure that there are translation and interpreter facilities. Professional workers should have an understanding of the culture of minority groups.
- Services need to be planned jointly with housing, the health services, education and the independent sector.

Source: Association of Directors of Social Services, 1990.

nities may at times define their needs differently from their white neighbours.

In particular, black and minority ethnic family styles may vary from those of the majority culture. Ideas about behaviour appropriate to various ages and roles within the family and outside it may also be different. At times, this can mean that the values placed on particular behaviours and activities vary from – or even conflict with – those of white British society. In addition, people from black and ethnic minority backgrounds' experience of services can be affected by racism. Box 4 explores these points further, using three case histories as illustrations.

From needs to services

An understanding of these basic needs, and the social and cultural context in which they are expressed, provides an underlying logic for developing services to support people with learning disabilities as they move through their lives. Most of the authorities that have been involved in the King's Fund programme have worked from this basic understanding using two additional ideas to guide service development:

- **A focus on the individual**

  Services should be organised to meet the unique needs of each individual in their own family or cultural setting and delivered in ways which support rather than supplant informal relationships. This means regular assessment and review of the needs of each person, and of his or her family, in consultation with them. Plans should be individualised, and their implications should be made clear. Where this involves interpretation or translation into another language, this should be done.

- **Accessing opportunities and services available to everyone**

  People with learning disabilities and their families need the same sorts of support and services as others living in the community. Some of this should be provided by special services. Much of it should come from the ordinary services which are available to everyone – for example, schools, health centres, libraries, further education colleges, leisure centres.

In detail, this means that local joint plans for service development need to address:

1 Support for family living

The security of a loving family provides children with the best setting for social and emotional development. Close relatives – mothers, fathers, brothers, sisters, grandparents, aunts, uncles and cousins – are also best placed to provide continuity throughout the lives of people with learning disabilities.

Services can support family life through offering:

- **Help and advice from paediatric and child care teams**
  This means well-judged handling of the process of diagnosing impairment and handicap; psychological and emotional support for parents as their child develops; as well as practical advice about how to cope with their child's particular disabilities.
- **Financial assistance to parents**

  Families need advice about the benefits they can claim to offset costs arising from their child's disability.
- **Help to encourage child development**

  Families may need help to acquire the skills they need to stimulate their child's growth and development. Increasingly, professionals are learning to do this in partnership with parents, and in the child's own home, rather than in specialist centres.
- **Specialist help**

  Some children will need help from speech therapy, physiotherapy, psychology and other remedial services.
- **Home care**

  Some families may need sitting services or help from care attendants.
- **Respite care**

  Some families may need a break from caring, or special help over an illness or emergency, for example, through assistance from another family that knows the child well.
- **Pre-school activities**
  Families may need help getting access to local mother and baby groups, nurseries, pre-school playgroups, clubs and other activities

BOX 4 Double discrimination: three stories

Carlton

Carlton is eighteen. He was born in Britain, and his origins are Afro-Caribbean. He had a lot of bad experiences at school, including being beaten by teachers. Once, on an organised outing, he was accidentally shot with a pellet from an air gun.

As a result of all this, his mother took him out of school. She became very worried about letting him go out on his own, and kept him indoors.

Carlton's life took a turn for the better when he met Lennox, the young man who became his advocate. Lennox, too, is of Afro-Caribbean origin, and was born in the UK. In fact, the two men had known each other in childhood. Their shared background has become an important bond, and Lennox has become a real companion to Carlton. Their friendship is important to both of them.

Nazir

At fifteen, Nazir is one of four children. As he has grown up, he has assumed responsibility at home. He is increasingly protective of his widowed mother, and makes sure that his younger brothers and sisters help out at home. Nazir's mother is very proud of him, and values the way that he looks after her.

Nazir's 'big brother'-style behaviour has carried over to the special school which he attends, but staff there interpret his behaviour very differently from the way his family do. One commented:

> *As he has got older the Asianness in Nazir is beginning to come out. He orders us around because we are women and is aggressive with it. He is always asking if we have done the teas and telling us when it is time for a break.*

As a result, Nazir is becoming more isolated at school.

BOX 4 *continued*

Carol

Carol is a 28 year old Afro-Caribbean woman, with mild learning disabilities. A personality disorder which developed during adolescence meant that she was put into care at 14. Since then, periods of living independently have alternated with life in an institution.

Carol was living on her own when she became involved with a man who lived in a nearby hostel for people with learning disabilities. She was happy when she became pregnant by him. However, her boy friend was moved, and she seems to have been forced to have an abortion.

She was very distressed by this, and her behaviour became increasingly disturbed. Although Carol is desperate for close relationships – particularly with men – she is also deeply distrustful of them. She began to be aggressive.

Carol spent a year in a large hospital, and was discharged from there to a flat in a white middle-class area. There, she lived with elderly people who resented and feared her, and expressed their feelings in very racist terms.

Staff changes affected Carol's ability to cope, and she began to damage furniture. When supervision was tightened, she rebelled and hit a member of staff, who is claiming criminal injuries while refusing to work with "the black bastard", even with additional support and safeguards. Although the police have brought no charges, staff fear that if a similar incident occurs, Carol will be admitted to a psychiatric hospital.

These unfortunate events have had a positive outcome, however. They have helped staff to recognise the isolation and disadvantage that Carol has experienced, and to plan some positive action. Currently, three of them are working extra time in order to give Carol the help she needs to live independently.

Source: Baxter, Poonia, Ward and Nadirshaw, 1990.

for growing children that will create links between them and other families locally. Extra help may be needed to ensure that children with learning disabilities contribute fully to these activities.

- **'Alternative' family life**
  Children who cannot be cared for within their natural families need opportunities for care within foster or – where appropriate – adoptive families.

2 A Real Education

Children with learning disabilities need opportunities for learning based on the National Curriculum. Wherever possible, these opportunities should take place in ordinary schools and colleges, alongside their contemporaries. In addition, each child should have:

- **Clearly defined educational objectives**
  These should be drawn up and reviewed in collaboration with parents.
- **Effective specialist help**
  Some children will need extra support with learning, or specialist advice from teachers and/or therapists in the classroom.
- **Good communication between home and school**
  This can be particularly important for students with learning disabilities, in order that new skills are transferred from home to school (and vice versa).
- **Careers advice**
  As a child prepares to leave school or college, he or she should receive effective careers advice and help with obtaining work.

3 A home to live in

When they grow up, people with learning disabilities need access to a range of locally available supported housing. This should include single tenancies in ordinary houses or flats, with staff support as individual needs require, as well as provision for small groups of people to live together with help from staff.

4 Occupation and work

People with learning disabilities need a range of day, evening and weekend activities which should give them opportunities to be part of their local community, alongside their contemporaries. Wherever possible, this means that they should be supported to find, and then to keep, real jobs, in ordinary workplaces, rewarded by fair pay for the work involved.

Work and other activities for people with learning disabilities should be designed to meet individual needs. Individuals and their families should have full information about a range of available options, and the chance to make real choices.

5 Advice and information

Throughout their lives, people with learning disabilities, and their families, will need advice and information on a variety of topics, including:

- Income support
- Housing
- Aids and adaptations
- Available services

It will be important for all forms of advice and information to be carefully gauged to the culture and language of local people.

6 A personal income

Whether it comes in the form of income support and benefits or as wages for work – or a combination of the two – a personal income, and the opportunity to make choices about how it is spent, is an essential part of adult life.

7 General health care

People with learning disabilities should have access to the primary and secondary medical and dental care available under the NHS to the community that they live in.

8 Special services

Some people with learning disabilities have problems caused by mental illness or by behaviour that other people find difficult to cope with because it is self-destructive or violent. First and foremost, people with these additional difficulties need access to high quality services designed along the lines suggested above. In addition they may at times need extra help, including:

- Help to change behaviour
- Detection and treatment of mental illness
- Additional care during episodes of mental illness

In all the authorities where the new thinking is evident, this sort of prescription for comprehensive services is understood not as a static blueprint but rather as a dynamic picture. This means that it is always subject to review, clarification and further specification in the light of user experiences and what providers themselves are learning about better ways of realising the key principles in practice. Section 3.3 explores how these efforts to develop positive visions of the future can be grounded in the individual experience of people with learning disabilities.

3.3 Putting people first

'People First' is both the name and the objective which people with learning disabilities have chosen for their self advocacy movement. At first sight, it seems axiomatic that public services designed to provide community care should put the people using these services first in their considerations. In practice, however, doing this creates a fundamental challenge to enabling and providing agencies. Following the discussion in Section 3.2, it can be seen that 'putting people first' has a number of overlapping components:

- it means starting from a commitment to people with learning disabilities as fellow citizens who may need support to live fulfilling lives in the community;
- it means thinking of people with learning disabilities as children, young people or adults first – that is, sharing aspirations and concerns with other people of similar age and backgrounds – and considering differences that may arise from disability as secondary;
- it means making the uniqueness of individual people the focus for designing and delivering appropriate support, rather than trying to fit people into categories or slot them into existing group provision;
- it means supporting people with learning disabilities in their efforts to increase choice and control in their everyday lives; and
- it means recognising the legitimacy of collective attempts by people with learning disabilities and their relatives and friends to influence the opportunities and services available.

At least some of these issues have been an important concern in all the places where the King's Fund has been working. Quite commonly, as in Wales, a welcome commitment to consumer involvement has left the definition of 'consumer' ambiguous. Much of the participation in shaping local services has mainly involved relatives – particularly through organised parent groups – rather than people with learning disabilities themselves.

Relatives – both because of family ties and as the main providers of care – do have an essential contribution here, both in relation to the individuals they know best and in collective advocacy. However, this Section gives more attention to the contribution of people with learning disabilities. Figure 7 provides a summary of the different ways in which people with learning disabilities and others advocating on their behalf have sought to put 'people first'. It distinguishes action at the level of individuals, at the level of particular elements of local service provision and at the strategic level.

As individuals, people have been seeking more control over their own lives. In places like Manchester, Richmond and Sheffield they have been supported by organised 'citizen advocacy' schemes. 'Circles of support' made up of family, friends and other concerned people are another, more informal, way of providing help and advocacy.

Locally there has been considerable growth in self-advocacy groups both linked with particular services – like Adult Training Centres – and geographical areas. People with learning disabilities are also becoming involved in collective advocacy through voluntary associations and coalitions. A good example at national level is the participation by People First representatives in the Independent Development Council for People with Mental Handicap.

As the right-hand side of Figure 7 summarises, public authorities have played an important role in both encouraging and responding to these initiatives.

Responses at the individual level

In direct work with individuals, it is critical that delivery staff – both those involved in assessment and case management and those providing services – are themselves committed to enabling people with learning disabilities to exercise more control over their lives. They also need the flexible skills required to support people in gaining access to community opportunities for education, employment and leisure and widening their network of friendships. Surveys, for example a recent Welsh office study (1989), show that the extent to which people with similar disabilities are able to influence quite basic aspects of daily life varies considerably. This remains an important concern for service design, operational management and staff training.

In some services, new roles have been established to give particular emphasis to promoting community integration, for example, community workers in Bristol; the supported employment team in Tameside; and the adult family placement team in Bolton. In these and other places there have been a variety of initiatives to promote and maintain friendship networks.

Figure 7 **Involving people with learning disabilities, their families and friends**

Level	Forms of involvement	Positive agency responses
Strategic	• Collective advocacy - encouraging public support - political lobbying - building coalitions - representation in planning - promoting mutual aid - using the law	• Developing partnership • Participation in policy making and planning • Funding voluntary organisations for mutual aid and advocacy • Actively seeking consumer views • Providing information and public education
Local and service element	• Local collective advocacy - encouraging access to community resources - representation in service management - reviewing quality - promoting mutual aid - fostering friendship networks	• Developing partnership • Participation in advisory committees and quality review procedures • Support for informed choice by users • Services sensitive to gender, ethnic and other differences
Individual	• Individuals gaining more control over community living • Self advocacy • Citizen advocacy • Circles of support	• Commitment to enabling and empowering among delivery staff • Person-centred assessment and individual planning • Individual contract specifications • Case management

From the perspective of the enabling authorities, some of the key proposals in *Caring for People* have considerable potential for underpinning and strengthening these developments if appropriately implemented. Specifically, the processes for assessment, individual planning, contracting and case management all offer vehicles for 'putting people first'.

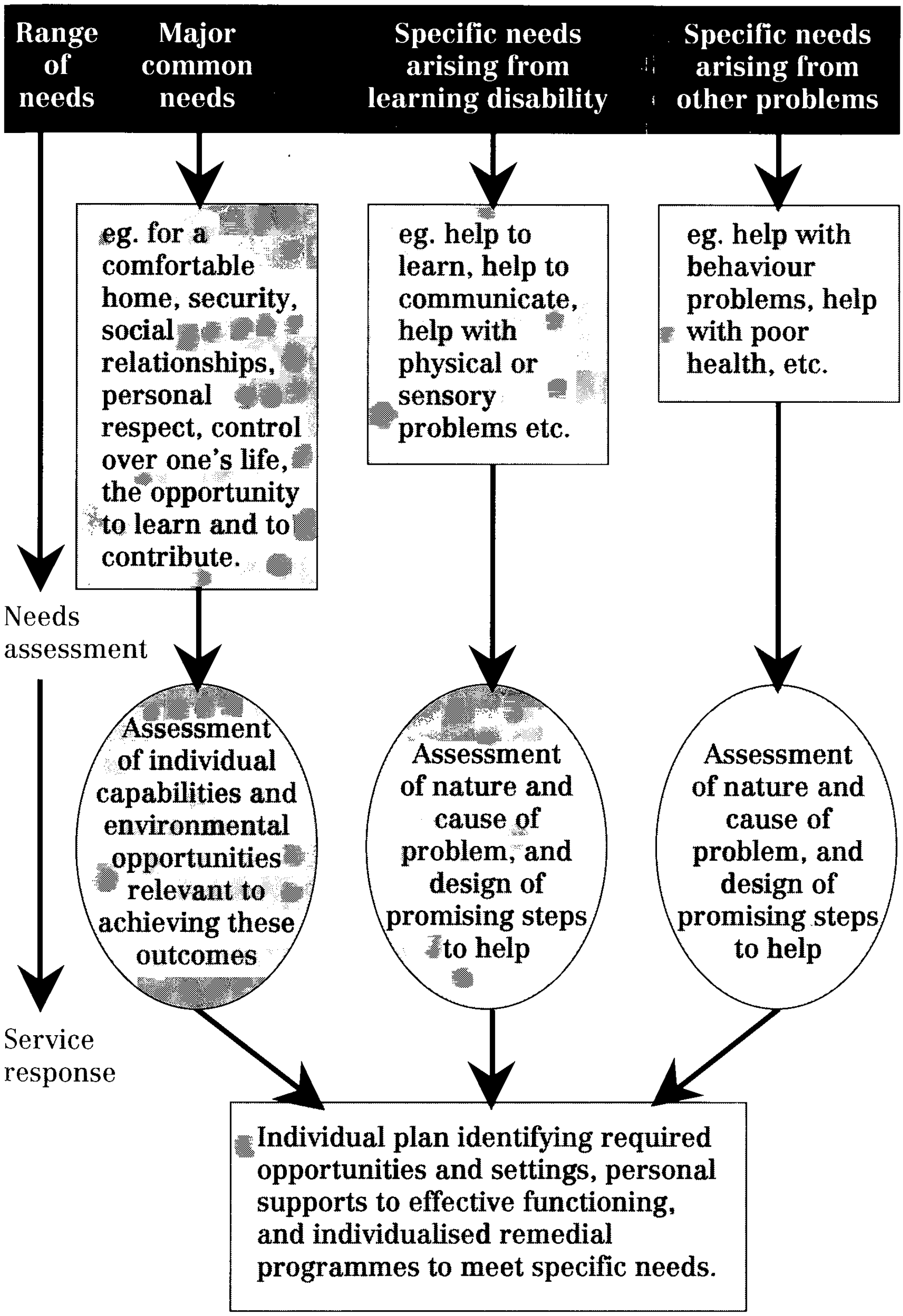
However, experience suggests that this potential strength is only likely to be realised where these processes are informed by a holistic framework for assessment. They also need to be carried out in ways which themselves promote positive outcomes for the person concerned. Box 5 summarises two different assessments of the same man: the first, undertaken by professional staff focusses on his disabilities as a route to determining the specialist services which should be offered as part of his individual programme; the second involved the man himself, family members and neighbours in identifying his capacities and local opportunities in order to find better ways of enabling him to live a fuller life.

Conceptually, the latter – more positive – approach sets the assessment within the context of planning for a desirable future, as suggested diagrammatically in Figure 8 (based on All Wales Advisory Panel, 1991b). Procedurally, a variety of tools are available to assist the assessment process, perhaps the most generally useful of which is the personal futures planning guide which informed the second assessment in Box 5 (and which is described more fully by Brechin and Swain, 1987).

Assessment and individual planning of this type is necessarily a continuing process. Public authorities are also required to undertake more formal procedures at particular times. These include statements of special educational needs under the *Education Act* 1981; assessments for services under the *Disabled Persons Act* 1986; and more explicit assessments of need under the *NHS and Community Care Act* (when this provision is implemented). Elsewhere, notably in the Australian State of Victoria's *Intellectually Disabled Persons' Services Act* 1986, legislators have made preparation and review of individual plans by the State agencies in consultation with people with learning disabilities a mandatory requirement.

Experience suggests that to the extent that these procedures provide entitlements and/or focus attention on individuals, they can formally reinforce – but not replace – the approach to individual planning described here. As the first example in Box 5 suggests, it is

Figure 8 **A framework for individual assessment and service response**



BOX 5 Two assessments

The text in italics is two different assessments of the same person – Mr Edward Davis.

The first one was done by a multidisciplinary team of professionals as part of a regular case review cycle. It brings together information from psychological, social work, nursing, speech therapy and occupational therapy assessments along with a review of progress in a sheltered day care setting. The aim was to make proposals for the next year's therapy and programme objectives. Mr Davis did not attend the meeting at which this assessment was devised because his violent behaviour had resulted in exclusion from his day centre on the day that the assessment took place there. No one from his family was present either, although they had been invited to attend.

The second assessment took place at the suggestion of Mr Davis' day care organiser and was done by Mr Davis, members of his family, neighbours, members of his church and two of his social care workers with the help of an outside facilitator. The aim of this assessment was to share information and concerns about Mr Davis' present situation, and plan for the future.

1 *Mr Davis has a mental age of 3 years, 2 months. IQ = 18. Severe impairment of adaptive behaviour, severe range of mental retardation. Becomes agitated and out of control. Takes (medicines) for psychosis.*

Severely limited verbal ability; inability to comprehend abstract concepts. Learns through imitation. Has learned to unlock the Coke machine and restock it, and to crank a power mower and operate it.

His family is uncooperative. They break appointments and do not follow through on behaviour management plans.

BOX 5 *continued*

2 *Ed lives with his mother and sister in (housing project). Ten of his relatives live near by and they visit back and forth frequently. His father spends little time with him, but two of his sisters have been very helpful when there are crises. His family agree that he will live with one or another of them for the rest of his life.*

Ed is at home in his neighbourhood. He visits extended family members and neighbours daily. He goes to local stores with his sisters and helps with shopping. He goes to church. Ed dresses neatly, is usually friendly, and shakes hands with people when he meets them. He is a very big man, with limited ability to speak. When he gets frustrated and upset he cusses and "talks" to himself in a loud voice. These characteristics often frighten other people who do not know him well. He has been excluded from the work activity centre because he acts "out of control" there. He has broken some furniture and punched holes in the walls there and scares some of the staff people very much.

Ed likes people and enjoys visiting in the neighbourhood. He loves music, dancing and sweeping. He likes loading vending machines and operating mechanical equipment. He likes to go shopping. He likes to cook for himself and for other people and can fix several meals on the stove at home. He likes to hang clothes and bring them off the line. He likes to stack cord wood and help people move furniture. He prefers tasks that require strength and a lot of large muscle movement.

Source: Mount and Zwernik, 1988.

all too easy – particularly in a climate where rationing is the dominant consideration – for these assessments to become service driven, deficit-oriented and insensitive to user and family preferences.

Successful authorities are therefore trying to combine the formal with the informal, and link this to the new arrangements for case management and purchase-of-service contracting discussed further in Section 3.4.

At local level

Turning to local arrangements for the provision of services, some public authorities and voluntary agencies have been actively promoting new opportunities for user involvement. To do so, they have offered people the support they need for more confident participation.

In the North West, for example, there have been a series of 'participation workshops' designed to help both people with learning disabilities and staff overcome the 'mutual handicaps' which impose barriers to working together. This has been useful preparation for user involvement in the planning and management of local services which have taken place through planning days in Rochdale, house committees in Burnley and day services advisory committees in Lancashire. There have been similar developments in voluntary agencies providing services and, in the housing field, increasing attention to educating people in their rights as tenants (with experience in Newham now illustrated in a video training pack – Allen and Scales, 1990). In some places too, there are growing efforts to involve users of services in quality review procedures (as in the Grimsby example, described in Box 12).

These developments need to take their place alongside – but be clearly distinguished from – arrangements for consultation with parents and relatives. Box 6 summarises proposals from a local advisory group for user, relative and advocate involvement in the development of community services to replace a long-stay hospital as an example of how this might work for one locality.

At the strategic level

When authority-wide policy-making and planning takes place, agency interest in user involvement has often formed part of wider trends encouraging more responsive public authorities. Many local authorities, for example, have been considering ways of 'getting closer to the public'. A number of social services departments have formal policies to involve users in the provision of services. However, these initiatives vary in the extent to which users and their representatives gain greater influence or control.

In some places, partnership between public agencies and organised advocacy groups has been an important pressure for progress in service provision. Some of the best examples come from North America where in States like Nebraska there has been many years of both overt and covert collaboration between senior managers of disability services and the Association for Retarded Citizens. State Disability Councils have provided a formal forum for dialogue among the different parties, sometimes by using public education or service development budgets. In Wales, the All Wales Mental Handicap Strategy requires that Counties demonstrate they have consulted with consumers in producing their plans and parent groups are typically represented in the county joint planning teams.

In many places this capacity for partnership is both fostered and complicated by public funding of the voluntary agencies taking up this advocacy role. This includes some recent examples of funding for professional advice and advocacy. Elsewhere, for example in Kent, the public authorities have used survey methods to seek user views. In the City of Birmingham, there has been a cumulative programme of initiatives designed to ensure that service provision is informed by the experience of users and unpaid care-givers.

Public agencies also have an important role in providing information about plans and services and contributing to public understanding about the importance of community integration for people with learning disabilities.

In all these functions, there is a particular need for authorities to consider how to encourage and support greater participation by people from black and ethnic minority communities.

Developing the forms of involvement identified in Figure 7 is problematic, particularly of course with people with severe disabilities. However, the experience of the last decade indicates that where authorities are clear about the importance of user participation at these different levels; are prepared to work with people in addressing difficulties; and are willing to change traditional ways of operating, then it is possible over time to move towards public services which really *serve*.

BOX 6 Partnership in developing community services to replace Normansfield hospital

The 1988 NDT report on services in the London Borough of Richmond argued that Normansfield Hospital should 'engage parents and relatives positively in the process of change and in monitoring the quality of resettlement programmes and quality in the hospital as it contracts'. In response the relatives association made the following proposals for a new *partnership:*

Our starting point is the view that while the public authorities and their paid staff have the primary responsibility for developing decent quality opportunities and services, they can only discharge this responsibility successfully in a genuine spirit of partnership:

- partnership with people with learning disabilities who wherever possible should have the opportunities to make informed choices about their own lives;
- partnership with citizen advocates who volunteer to speak up for people whose interests may otherwise be inadequately recognised;
- partnership with relatives who often know people best and have been, or may still be the main carers, and
- partnership with members of the community whose interest will be important if people with learning disabilities are to live more ordinary lives.

There seem to be three general requirements in building a strategy for the future based on partnership:

1 Real commitment to this among managers and professional staff, demonstrated through creating a wide range of opportunities for participation and growing skills in encouraging such participation;
2 Investment in designing and establishing appropriate arrangements for participation in relation to individuals, groups (eg. the residents of a particular house), Normansfield and the district as a whole;
3 Interest from and support for people with learning disabilities, relatives and community members in sharing in this extended variety of opportunities.

If this challenge is taken seriously, it should over a period be possible to test the usefulness of a number of different arrangements, including:

At the individual level

1 Further efforts by staff to ensure that wherever possible, people with learning disabilities are supported in identifying choices and expressing preferences about all aspects of their everyday lives so that they grow in capacity for

making individual choices and have the opportunities to pursue these choices.

2 Independent support for the growth of self-advocacy through enabling groups of people with learning disabilities to share their experiences and develop skills in acting on their own behalf.

3 Substantial expansion in support for citizen advocacy so that anyone who might benefit will have an interested member of the public prepared to befriend and speak up for him or her.

4 An independent advocacy office where any person with learning disability and any relative can seek advice and support in pursuing the interests of the person with learning disability.

5 A revised approach to individual programme planning which ensures that on a regular basis there is a proper approach to improving the life situation and planning the future for every person with learning disability, which involves the person him/herself, relatives and advocate.

6 Introduction of a proper case management system to ensure that each individual has a named member of staff responsible for putting together the best possible package of opportunities and services for him or her and checking that these services are delivered as planned.

At the small group level

7 Introduction in each element of the local service of user committees which offer people with learning disabilities the opportunity – wherever possible – to contribute to the management of that service or facility.

8 Similar investment in consultation between staff, relatives and advocates about each element of the service.

9 Introduction of explicit quality assurance procedures for each element of the local service in which users, relatives and advocates would be involved.

10 As services in the community develop, investment in careful efforts to promote opportunities for people with learning disabilities to get to know ordinary people from their neighbourhoods, workplaces and leisure pursuits.

For Normansfield as a whole

11 Further efforts from management to keep residents, relatives and advocates well informed about plans for change and the progress being made.

12 Continuing staff participation in the regular meetings of the parents and relatives associations.

13 Complementary invitations to representatives of the relatives and advocates to participate as advisers in key policy-forming groups for Normansfield and for the District.

3.4 New ways of working

In order to promote positive outcomes for people with learning disabilities there is a need not just to develop new opportunities and services but also to change the ways public authorities and providing agencies go about their work. In the case of the public authorities, the shift towards a stronger enabling function implies an enhanced strategic role in enabling communities to meet local needs. It also means a greater capacity to work with and through other agencies in a pluralist pattern of provision. As the *Caring For People Policy Guidance* puts it:

> the role of an enabling authority is to identify the needs for care among the population it serves, plan how best to meet these needs, set overall strategies, priorities and targets, commission and purchase as well as provide necessary services and ensure their quality and value (DoH, 1990).

Those responsible for service management within the public agencies and independent providers have to develop their capacity to work within these commissioning arrrangements. They also need to respond to the increasing emphasis on services tailored to meet individual needs and wishes.

The trends in this direction have accelerated recently, particularly as authorities grapple with the implications of the *NHS and Community Care Act,* 1990. For the public authorities, this has posed four main challenges.

First, greater explicitness in assessing population need and defining priorities at a time of severe pressure on resources is requiring political decisions on the balance between the quality and intensity of services and the extent of coverage. Given the 'low base' from which much local provision starts, there are no easy solutions to these rationing dilemmas, but a common view is that progress in the medium term requires 'targeting' of effort so that quality is not put in further jeopardy.

Second, in many places the pressures for organisational change – including those generated by the mass of Department of Health guidance – have risked displacing attention from 'ends' onto 'means'. To combat this, authorities have seen the importance of local change strategies which combine a clear sense of how the lives of vulnerable

Figure 9 **Enabling and providing agencies in a comprehensive pattern of local services**

Planning and Purchasing Authorities	Local Authorities, including Education, Social Services, Housing and Economic Development Departments	Family Health Services Authorities	District Health Authorities

Opportunities and services to meet individual needs

family support education employment accommodation home care general health care specialist treatment

early intervention training recreation transport respite care special needs support

welfare rights and income support

Potential providers

- Social Services Departments
- Self-help groups
- Voluntary agencies

- Education Departments
- Locally-managed schools
- Employment Bureaux

- Local employers
- Employment initiatives
- Recreation departments

- Sheltered work schemes

- Housing Authorities
- Housing Associations
- Landlords

- Families and friends
- Alternative families
- Private care agencies

- General practitioners
- Dentists and Pharmacists
- Volunteers and advocates

- NHS specialist and community services, including medical, psychological and paramedical therapists

- Welfare rights departments
- Advice Bureaux
- Department of Social Security

Source: NWRHA, 1990

people might be improved along with direct user involvement in shaping new services and the development of new ways of working.

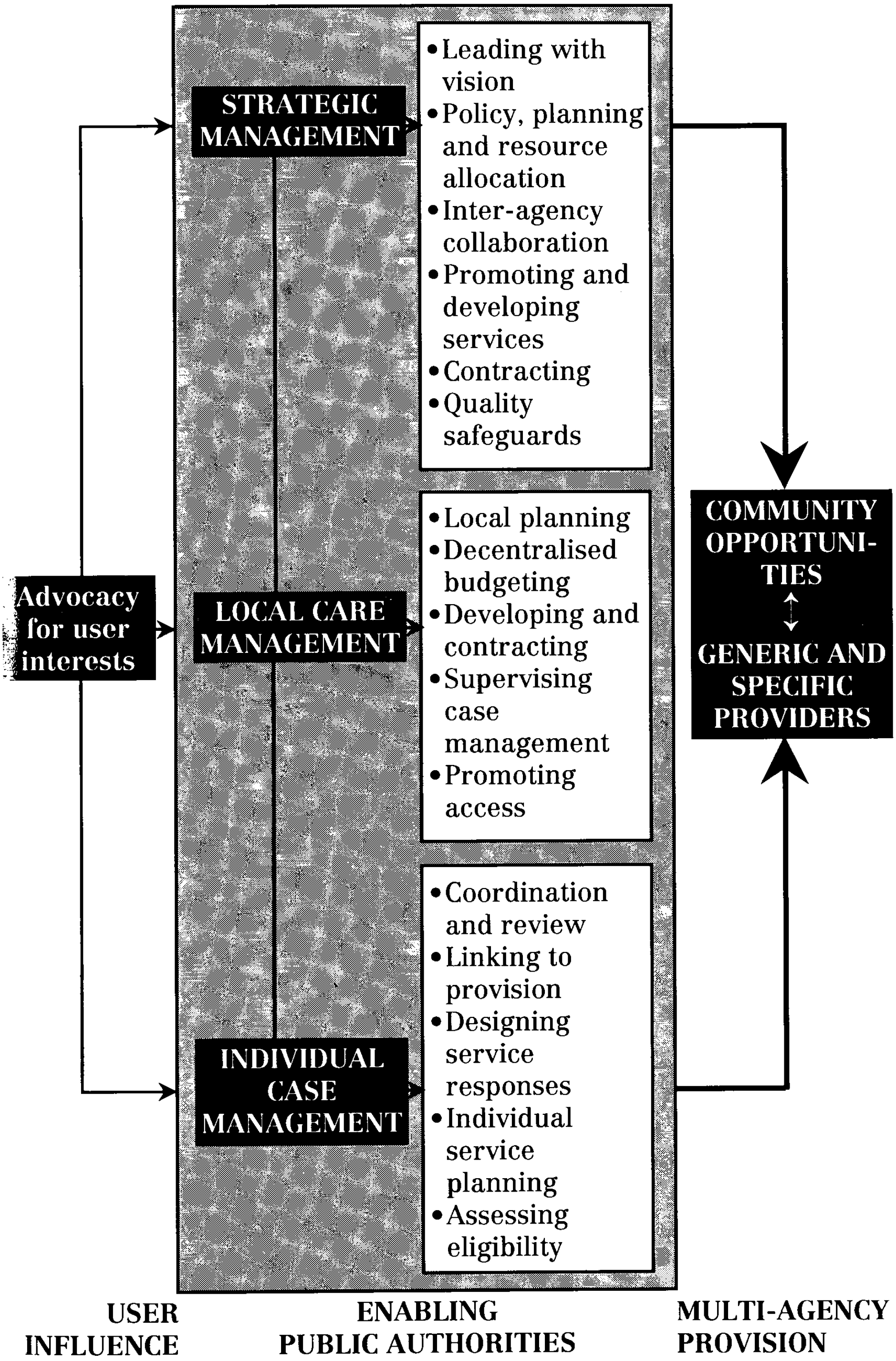
Third, the huge managerial agenda for each type of public authority and the differences of emphasis and timing in relevant central policies has increased the dangers of unilateral responses to these new requirements. Again, by contrast, effective public authorities are identifying the importance of interagency collaboration both to fashion locally-relevant joint approaches and to mobilise the widest possible range of resources. As Figure 9 suggests this partnership is particularly important in meeting the needs of people with learning disabilities, for whom community living necessarily implies an extensive variety of supportive contributions.

Fourth, as research on the Welsh experience shows (for example, McGrath and Grant, 1989), even where there is a coherent national policy framework, it can prove difficult to achieve a real shift towards devolved, needs-led planning and appropriate user participation. In counties like Devon, Hampshire and Humberside therefore, the strategic authorities are investing in approaches which start from piloting new ways of developing services around individual clients before seeking to introduce wider cultural, organisational and procedural changes.

It is possible to identify the essential characteristics of these new ways of working by extrapolating from these incremental approaches. Examining the North American experience of purchase-of-service contracting and the mixed economy of welfare is also helpful. The development of the enabling role requires that authorities combine their responsibilities for strategic leadership with the decentralisation necessary to ensure that services are designed – and money is spent – close to users. In turn this requires skilful management of the triangular relationship between strategic planning, the purchase and provision of services and individual service planning (identified in Figure 5).

In Figure 10, the three components of the triangular relationship in Figure 5 are elaborated. The box on the right-hand side represents the variety of opportunities and services, generic and specific, public and private, suggested in Figure 9. As in Section 3.3, the central column identifies three 'levels' of management in the enabling authorities and summarises key functions at each level. Expanding Figure 5, this suggests that – in addition to authority-wide strategic management and individual case management – an area-based care

Figure 10 **Managing pluralism in opportunities and services**



management function at middle management level is likely to be necessary. Public authorities also need to make *separate* organisational arrangements, for managing their own directly provided services (which contribute to the right-hand box) and for their regulatory functions – for example, in social services departments, the 'arms length' inspection units required by recent legislation.

Well-developed versions of this model are visible in States like Arizona, Massachusetts and Wisconsin. In Massachusetts, for example, the regional offices of the State Department of Mental Retardation – which serves populations equivalent to large English counties – are responsible for strategic management within broad policies, fiscal parameters and regulatory arrangements established at State level. The regional office in Western Massachusetts establishes the principles to be reflected in local services, defines priorities, negotiates budgets with the area offices and defines the procedures for purchase-of-service contracting. Operational tasks involved in care management are devolved to area level – for example, for Holyoke-Chicopee, serving a population of 180,000 – where the local director manages two teams. These consist of:

- **Case managers** each working with around 30 individual clients They establish eligibility; develop individual service plans; negotiate with the director over the costs of implementing these plans link individuals to opportunities and services and coordinate different elements of the care package; and

- **Service development and contracting staff** responsible for fostering independent providers. All local services except case management are provided under contract, mainly through small not-for-profit organisations. Service development staff manage a competitive tendering process in which these providers are invited to bid for contracts which meet the requirements being identified in individual service plans.

In these arrangements, the key link between Departmental policies, individual plans and local provision is the 'request for tenders' documents which define the policies and standards to be met by providers; the clients to be served; the objectives to be met by providers for these clients; fiscal arrangements; and how performance will be monitored.

As authorities here move in this direction, three aspects of these requirements are receiving particular attention:

- the need for strategic planning in multi-authority systems;
- the decentralisation of care management and introduction of assessment and case management arrangements; and
- the development of purchase-of-service contracting.

As Figure 9 illustrates, the division of responsibilities between authorities and departments in public authorities, each with their own planning and commissioning roles, requires renewed attention to the implications for joint planning in the context of education, social services and NHS legislation. If services for people with learning disabilities are to be 'seamless' from the users' perspective, there must be local efforts to agree agency responsibilities; identify leadership for service development for clients at different points in the lifecycle and with different requirements; and develop joint operational arrangements both for assessment and service delivery.

This is a complex challenge. In some places local and health authorities are addressing these requirements by building on previous experience of joint planning to produce the community care plans required by *Caring for People.* Elsewhere, steps are being taken to simplify the tasks. This can mean one authority taking on the main planning and development functions as in Somerset, where the social services department has taken the lead in developing community services, including those for people leaving NHS institutions. Alternatively, it can involve an early transfer of finance and management responsibilities for one authority's services to another, as in Richmond, where NHS residential services are being managed by the social services department. It can also mean establishing new umbrella organisations, either as a way of pooling purchasing power, or coordinating provision or both. These often incorporate housing associations.

As authorities like Devon County Council are showing, the requirement to produce, publish and consult on the community care plan provides a new vehicle for pooling intelligence on population needs and building a vision of desired outcomes into inter-authority agreements (Devon County Council, 1990). It also requires members and senior managers to make explicit their priorities and address the tensions between expected need (determined from epidemiological data and surveys as well as consultation with consumer groups and individual assessments); the cost of good quality, individualised, services; and the resources available. In Devon, this has included the publication of a 'Charter of Rights', designed to clarify what service users are entitled to expect.

These policies and priorities form the framework within which authorities are seeking to devolve management and budgeting responsibilities to care management systems which ensure that services are designed around individual needs and wishes.

Typically this devolution is being introduced on a pilot basis, as authorities seek to develop the necessary skills in middle managers and introduce new financial control and information systems. In doing so, many are seeking to learn from more established case management projects like those in Andover, Maidstone and Wakefield.

The commitment of case managers to working in partnership with users to design and implement forms of support which promote their integration in community life and minimise the effects of their disabilities is fundamental to the success of these projects. In addition, experience suggests that effective case management requires that the roles and authority of the case managers within the system of planning and provision are clearly defined; case loads are small enough to allow the key tasks to be properly performed; there are devolved budgeting arrangements and real choice among different forms of provision; and skilled management support for case managers in their work.

It needs to be stressed, however, that this emphasis on the enabling functions of public authorities and these new approaches to individual planning are only the means for ensuring that people with learning disabilities gain access to suitable opportunities and receive the support they require for community living. The success of these endeavours must still be measured by the outcomes in people's lives and the quality of service provision.

The shift towards more plural patterns of provision does not reduce authorities' responsibilities for mobilising expert contributions to service design and development, drawing on the best of what has been achieved over the past decade – see Box 7. Rather, it adds new requirements to stimulate a variety of relevant provision and to develop the capacity for purchase-of-service contracting.

Stimulating provision involves public authorities in using their planning, networking, service development and contracting capacity to create a provider 'market', and then to nurture it and shape its growth. This may include developing exemplary services which offer a model to others, or provide a 'fall-back' if other provision is found wanting. This can be done through directly provided services or through 'preferred providers' in the independent sector. In Holyoke-Chicopee, for example, the local office has promoted a key role for the Pioneer Development Centre, a not-for-profit community organisation, in providing family and adult support services, particularly to people with the most severe disabilities. Nearer home, the Camden Society for People with Mental Handicaps has played a similarly innovative role in the development of community-based services.

The 'market stimulator' role may involve public authorities' acting directly, or working through intermediate development agencies – for example, local Councils of Voluntary Service – offering assistance to small organisations to ensure their viability as contractors. This may be particularly important in avoiding the marginalisation of organisations for black and ethnic minority groups.

Appropriate purchasing requires a good understanding of the relationship between quality, cost, and staffing along with a willingness to reward provider achievements through the reimbursement formulae. The Department of Health's practice guidance on purchasing usefully describes how service specifications should vary in form according to the flexibility required in provision. It goes on to define the key issues to be covered in contracts and describes how performance can be monitored (DoH, 1991). Experience suggests that in selecting providers to meet particular specifications, purchasers will need to assess the quality of service design; the capacity of the agency to deliver its proposals; and their fiscal soundness.

All this has significant implications on the 'provider' side. Directly-managed services will need more entrepreneurial leadership which is able to take an active role in informing planning by the public authorities and, where necessary, a radical stance on the need to re-shape existing provision to meet quality standards. Authorities also need to ensure that 'units' of service provision develop their own business planning capacity and trading accounts. Independent organisations, particularly those in the voluntary sector, need to become involved in consultations about community care planning. They will also need to distinguish activities – like advocacy – for which grant-funding may be appropriate, from service provision – for which contracts will be required. At the same time they will need to develop

BOX 7 Using design expertise to produce service specifications and provider proposals

The shift towards purchase-of-service contracting does not reduce the need for both purchasing and providing agencies to attend to what has been learnt in recent years about the relationship between the design of services and achieving valued outcomes for users. These design requirements should be reflected in service specifications, in provider proposals to meet the specifications and in subsequent monitoring of performance.

There is a common 'logic' of service design across provision to meet different kinds of individual need. In each case analysis should:

- start from the assessment of individual need using the framework in Figure 8;
- formulate a clear statement of service aims, detailing what users would do and experience if the service is successful;
- identify the service responses required to achieve these aims;
- specify the key factors required to achieve good quality responses with particular attention to staff performance, service organisation and the settings within which services are delivered.

For example, there is now significant experience in providing an ordinary home life for adults with severe or profound disabilities, the best documented of which is the Andover project described by Felce and his co-workers. Attending separately to the major common needs of possible residents (e.g. for a home, for opportunities to participate in valued activities), specific needs arising from their learning disabilities (e.g. for opportunities to improve functional skills) and specific needs arising from challenging behaviour (e.g. to develop alternative stimulation and address neurochemical disorders), they identify service aims which include:

- providing a permanent home promoting individual development;
- promoting active engagement in ordinary living;
- developing alternatives to challenging behaviour;
- enabling community involvement;
- providing help with treatable disorders;
- enabling involvement with family and friends.

BOX 7 *continued*

By fully detailing what these aims mean for individuals identified as needing a residential service and analysing what is known about effective service responses, they are then able to define requisite service design features under each main heading:

Staff performance requires:

- clear ways of working based on individual client programmes, encouragement routinely for frequent appropriate interactions, access to ordinary opportunities and a well-organised day;
- positive monitoring through performance indicators which reflect key aims, regular staff meetings and quality circles;
- staff training on the skills required for the procedures, e.g. behavioural analysis, goal planning, teaching and positive interaction.

Service organisation requires:

- staffing levels and skill mix based on a summation of required performances;
- staff roles defined as supporters and motivators, with detailed job descriptions emphasising aims and methods, plus access to expert advice;
- management autonomy at the household level, with close attention to client grouping, staff deployment and activity planning.

Service setting requires:

- ordinary housing of small size;
- located close to community amenities and where possible to family and friends;
- furnishing and equipment which are domestically normative and provide a positive material environment.

Source: Felce, 1991.

their own trading capacity. Critically, providers of all kinds need to ensure that their proposals reflect a real understanding of the relationship between the outcomes intended for their clients, service design considerations and costs.

3.5 Managing transition

In order to offer people the new opportunities and support required for community living, public authorities must meet the challenges involved in transforming existing forms of provision. This applies particularly to segregated services, which remain the main options available to people with severe disabilities. Special schools, adult training centres, hostels and long-stay hospitals employ many of the staff and much of the financial resources which are needed to develop community-based alternatives. A recent Audit Commission report shows that nearly 60 per cent of the combined local and health authority budget for adults with learning disabilities is still locked in hospital provision (1989).

The challenge here is not just to shift the location of services and the people using them towards more integrated, local provision. Experience suggests that it is only too easy to produce 'old wine in new bottles' unless there is simultaneous investment in changing the cultural assumptions, staff performances and organisational processes which underpin traditional practice. Indeed this transformation requires attention to all the dimensions of strategic change identified in Figure 5. Within this wider context, there are a number of specific issues which must be tackled in managing the transition from traditional services. These are the topic of this Section.

The focus is on the process of resettling people from large institutions. This is the most dramatic example of change in provision, involving, as it does, the 27,000 people still subject to a lifetime's incarceration in English mental handicap hospitals. Resettlement has been a major thrust of national and local effort during the 1980s. As a result, the process is one in which there is now substantial experience, worthwhile success and some systematic evaluation. It is worth noting that many of the same issues also arise in getting children access to mainstream education and in offering adults opportunities for supported employment.

A regional perspective

The large catchment areas of the NHS institutions and the financial complexities involved in closing them typically mean that a regional or sub-regional perspective is required in planning change. The

King's Fund programme has worked on these issues with authorities in four English regions, Wales and the Australian State of Victoria.

In the South West, for example, the regional health authority, five county councils and eleven district health authorities were involved, together with other public, private and voluntary agencies. Under the broad slogan 'people not patients', the region's intent was to close all its institutions – housing more than 3,000 residents – within a decade beginning from 1985. Developing a coherent strategy for change required a wide variety of activities at different levels and in different parts of this large, multi-agency system.

It proved useful to distinguish three components of this strategy:

- establishing the strategic framework;
- designing and developing community-based services;
- managing the contracting institutions.

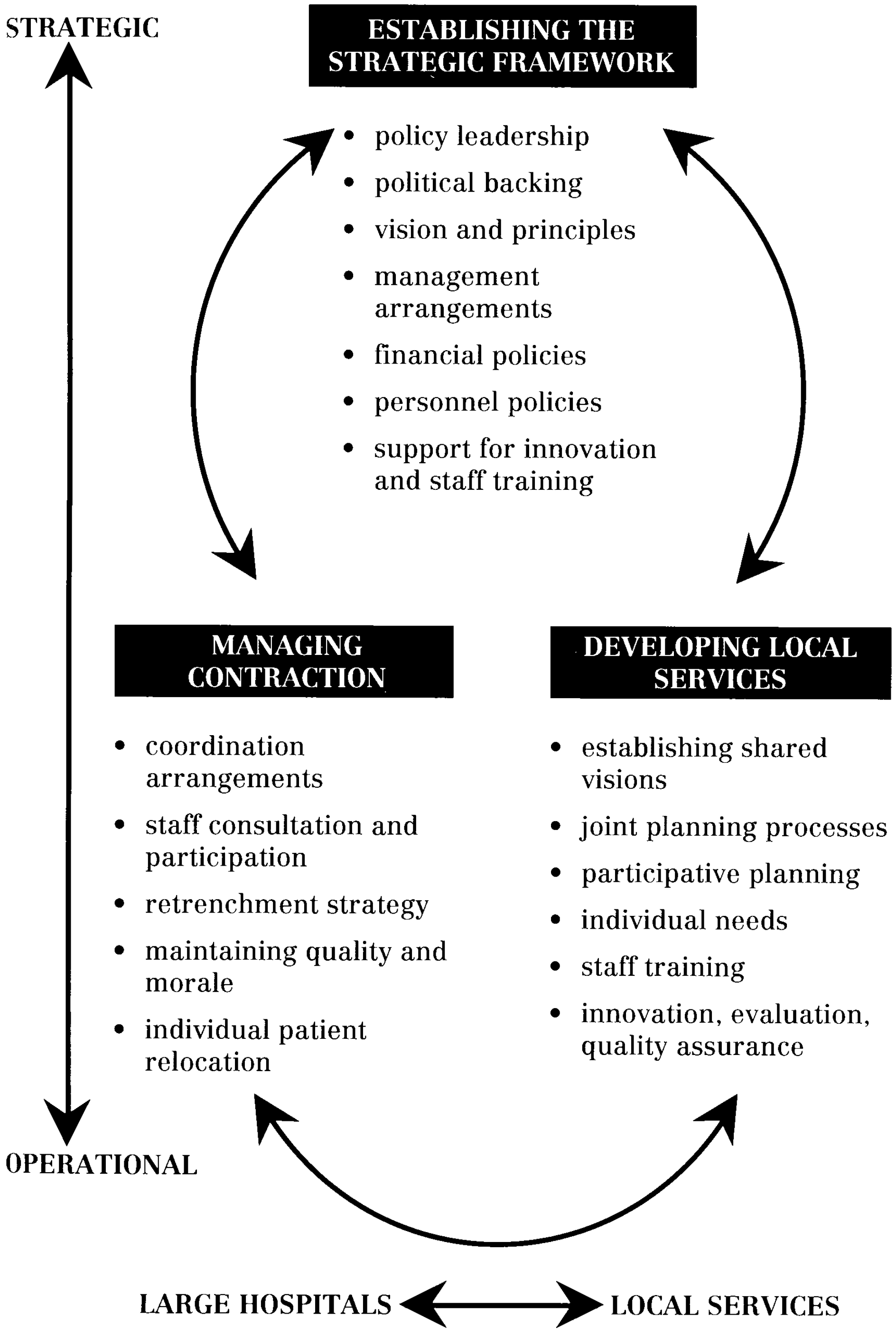
The strategic framework

Figure 11 illustrates the inter-dependence of these three components and identifies specific issues requiring attention. As has already been emphasised, successful pursuit of large-scale change over a long period requires a positive vision of future opportunities to energise the movement for reform throughout the system. In addition, much of the detailed work to develop community-based alternatives consistent with this vision can only be done through small scale initiatives close to individual service users. Large scale strategies need therefore to combine the broad strategic framework required to promote purposeful local action with effective decentralisation.

In the South West, the RHA took the lead in negotiating this strategic framework with the county councils. Policy makers addressed the rate of movement towards community-based services; the planning and management arrangements required to coordinate transition, financial and personnel policies; and the importance of encouraging user and family involvement in the process of change.

These authorities worked hard to develop collaborative arrangements aimed at promoting common goals and monitoring progress. Members and top managers from the NHS and local authorities met periodically to steer the regional strategy in the light of both national policy changes and local initiatives. The authorities also established

Figure 11 **Key issues in a concerted strategy for change**



STRATEGIC

ESTABLISHING THE STRATEGIC FRAMEWORK

- policy leadership
- political backing
- vision and principles
- management arrangements
- financial policies
- personnel policies
- support for innovation and staff training

MANAGING CONTRACTION

- coordination arrangements
- staff consultation and participation
- retrenchment strategy
- maintaining quality and morale
- individual patient relocation

DEVELOPING LOCAL SERVICES

- establishing shared visions
- joint planning processes
- participative planning
- individual needs
- staff training
- innovation, evaluation, quality assurance

OPERATIONAL

LARGE HOSPITALS ⟷ LOCAL SERVICES

two new vehicles for maintaining progress and learning from experience: a 'regional forum' for managers leading the process of implementation and a 'strategy support unit'.

The forum brought together RHA officers and representatives of other relevant agencies with implementation managers from each of the health and local authorities. It provided opportunities for exchanging information on local progress and problems, developing 'mutual aid' initiatives designed to improve performance and reviewing region-wide policies in the light of their local impact.

The strategy support unit was a multi-professional group of staff from different parts of the region. Its leaders were an NHS chief officer and a director of social services representing his colleagues. The unit acted as a device for pursuing these forum objectives continuously, offering advice both 'upwards' to the strategic authorities and 'downwards' to local services on ways of strengthening the prospects for success. Similar collaborative, monitoring and developmental initiatives have been important elsewhere, for example in the North West and in South East Thames RHA.

An essential component of these regional strategies has been the financial policies required to provide incentives for change; meet the extra costs of dispersed services; and 'bridge' the costs of transition. Different approaches have been tried. In the South West, an early decision was made to allocate the budgets for people in institutions to their 'districts of origin' so that authorities could identify their expenditure out of the district. As the institutions contracted and unit costs rose, authorities had an increasing financial incentive to 'bring their people back home', which reinforced the deinstitutionalisation policy.

Elsewhere in England, RHAs have established 'dowry' arrangements so that individuals bring with them a budget for developing local services. Typically, this is related to average hospital running costs, with the regions themselves meeting the shortfall in hospital budgets arising from the difference between average and marginal costs. Only in Wales has the regional authority – in this case the Welsh Office – made earmarked resources available to develop community-based services in advance of resettling people from the institutions.

There is now considerable evidence to show that the costs of good quality local services are typically greater – and for a few people considerably greater – than those they replace (Shiell, 1990). In the South West, as elsewhere, these differences have in part been covered by increased NHS allocations to improve standards, but the main shortfall has been met from the social security entitlements of people living in independent sector residential care. (A comprehensive analysis of the costs involved in replacing Darenth Park Hospital and how these are being met is provided in Korman and Glennerster, 1990).

This use of social security benefits has serious disadvantages, however. These include the perverse incentives it offers for particular forms of residential care; the likelihood of quality falling as the value of benefits declines; and, more generally, the constraints on 'ordinary life' which follow from inadequate personal incomes.

Personnel policies in the broadest sense were another necessary element in this framework. These involved negotiating the support of staff interests; identifying and planning for future workforce requirements; offering opportunities for staff to transfer to new services; and providing appropriate training.

Particularly where deinstitutionalisation also leads to a change in employment arrangements for care staff (as in Somerset), personnel policies which provide security and support to hospital staff, and which have trade union agreement, have been important to the whole process of transition.

Operational coordination

As Figure 11 suggests, these and other issues are also important at the operational level, as people are resettled, and institutional contraction is managed. Again, it is essential that proper coordination arrangements are established between the authority managing the hospital and those agencies developing alternative services in different locations. There may be several of these in relation to large institutions.

There is also an obvious need for project management which crosses the institution/local boundary to plan and implement resettlement for individuals and small groups. The views and wishes of hospital residents are crucial here. The great majority of people appear to prefer life in more normal settings (Booth et al, 1990 and PSSRU, 1990). At the same time, the personal anxiety involved in 'moving out' needs to be fully recognised.

Equally, relatives need to be properly involved in planning change and in developing better quality alternatives for the person

BOX 8 Planning hospital closure

Darenth Park Hospital was one of the oldest institutions built specifically for people with learning disabilities. It opened in 1878 as the Darenth School for 500 children, was expanded to accommodate adults, and a century later still housed 1000 people, offering the main NHS service to nearly half of the South East Thames region. Over the decade from 1978, the regional health authority – increasingly working with local agencies throughout this large catchment area – led a major programme to develop local alternatives to Darenth and close the hospital. By August 1988 all surviving residents had moved. In the early phases of relocation this was mainly to smaller NHS institutions. Increasingly, in recent years, people took up residence in ordinary housing influenced by the an ordinary life model.

This process was the focus for a major political and economic study by Nancy Korman and Howard Glennerster. They describe clearly the scale of the challenge in successfully managing the transition from institutional services, as a first step towards promoting the fuller integration of people with more severe learning disabilities into mainstream society. They also draw lessons for the key parties involved in planning other closures. These include:

For strategic leadership at regional level:

- Provide continuity in policy leadership and maintain the pressure for successful implementation.
- Promote a shared philosophy among key implementors to guide these changes.
- Adopt a 'tight/loose' approach in which principled leadership is combined with effective decentralisation and reinforced by economic incentives for action.
- Offer professional support on tackling local planning issues and brokerage services to unblock inter-agency conflicts.

BOX 8 *continued*

For local public agencies:

- Seek to involve relevant parties from the outset in shaping the new patterns of provision.
- Invest in a core group of staff with the seniority and expertise to lead and manage complex change.
- Invest in development work and be prepared to make adjustments in the light of mistakes.
- Establish processes for planning and monitoring services for individuals and ensure these address the full range of client needs.

For managing institutional contraction:

- Establish good 'lateral' relationships between the contracting institution and service developers in the 'receiving' authorities.
- Build in effective liaison at ward level between staff, residents and their relatives.
- Demonstrate commitment to existing staff and their redeployment.
- Examine all issues concerned with physical contraction and institutional maintenance from the perspective of the remaining residents.

For everyone involved:

- Recognise that relocation to decent housing with staff support is no more than a good starting point for developing a range of local opportunities, increasing client autonomy and promoting real integration.

Source: Korman and Glennerster, 1990.

they care for. Parents – particularly those whose sons and daughters have already spent many years in institutional care – typically have poor experiences of public services, limited knowledge of community-based alternatives and considerable doubts about proposals for change. Given this, it is not surprising that there has been organised resistance to deinstitutionalisation policies in many places.

Experience suggests that many of these doubts can be overcome where managers who know the residents make the time to explore the issues honestly with relatives; where there is skilled leadership available to help people address their own concerns; and most importantly, where parents are able to share the experiences of others who are already familiar with the opportunities offered by good community services. The London Borough of Richmond provides an example of this: the mother who movingly described how her son had begun to develop an adult relationship with her once he moved out to an ordinary house was the most persuasive advocate for community living in the relatives association at Normansfield.

Managing contraction

Finally, the institutions themselves require high quality management during contraction to maintain and where possible improve standards while resettlement and retrenchment are proceeding, and to encourage staff support for change.

All these issues are well illustrated by the detailed study of the closure of Darenth Park Hospital, summarised in Box 8.

Using the same 'map' as in Figure 11, Box 9 offers a briefer summary of similar lessons from the American experience of moving from segregated day centres to supported employment programmes

BOX 9 From day centres to supported employment

In Britain, the main day time provision for the great majority of adults with learning disabilities has been attendance at Adult Training Centres/Social Education Centres. This was once true in the USA but in several States there has been a significant change towards mainstream supported employment. This transformation is now growing in strength in Britain. The key steps in managing this change include:

- **In establishing the strategic framework:**

  - develop enthusiasm for supported employment among key parties;

  - review organisational arrangements and establish a change management team;

  - identify financial requirements;

  - assess staffing and training needs;

  - plan the phasing of change.

- **In developing employment opportunities**

  - survey the local labour market and interest employers;

  - match jobs to workers' needs, preferences and capabilities;

  - develop staff capabilities in the new roles of job coach and job developer;

  - link work, home and transport issues;

  - establish quality assurance procedures.

- **In moving out from the day centres**

  - involve staff, relatives and workers in planning change;

  - identify relevant capabilities among staff and provide training opportunities;

  - analyse alternative uses for the facility and related financial issues;

  - tailor new opportunities around, and prepare individuals.

Source: Jacobson, 1987

3.6 Developing staff *

Staff play a crucial role in services for people with learning disabilities because they mediate the opportunities which surround individuals but which, without help, they cannot access. Many people with severe or profound learning disabilities would not be able to take part in everyday household activities (such as housework, gardening, shopping) without staff to help them through each step of the task; and people with mild or moderate learning disabilities who can do most of these things often still need help budgeting, planning and keeping check on more complex areas of daily life. How well this help is provided is likely to be the most important determinant of the quality of life experienced by the individual service user.

How staff work with the people they serve is therefore a key focus of any attempt to improve services for people with learning disabilities. Staff performance is only partly a function of the kind of training staff have received; as Section 3.4 argues, it is also heavily dependent on service design. Service design involves giving very careful attention throughout the planning process and in the operational management of services to the impact of decisions made on how staff will work with clients; matching plans and management practices to the staff performance required and the client outcomes desired. Where they are badly matched, these decisions will hinder rather than support good staff performance (for example, undermining team cohesion by using agency staff, or building-in institutional catering). This is why it is unrealistic to expect the same achievements in institutional (hospital, hostel and day centre) environments as, for example, in good staffed housing and supported employment, irrespective of the training individual staff have received.

The training task

The training task is therefore rather broader than traditionally conceived. It involves working at organisational as well as individual levels, to create and sustain a climate in which local service providers

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* This section on Developing Staff was drafted by Jim Mansell. Professor Mansell leads the regional training initiative in South East Thames and is the Director of the Centre for Applied Psychology of Social Care at the University of Kent.

are able to establish good models of service, manage the transition from old to new and realise the potential of the new services in the community.

People leading the development of new services are often likely to be doing this against a background in which there is no clear policy mandate for community-based services as opposed to institutional solutions; where existing services and service agencies can be expected to respond to change with a degree of 'dynamic conservatism'; and in which simplistic ideas about services abound (that, for example, working with individuals who have severe or profound learning disabilities is unskilled work, or that size of residential facility is irrelevant).

Solutions imposed from the top are not likely to work well in this situation. They will be over-prescriptive of the wrong targets and better-informed local innovators will work to subvert them with what they see as better solutions. The challenge for senior managers is to provide a facilitative framework which stimulates service development and accepts that plans will change as experience and confidence grows. An example was the ten-year programme in South East Thames region to replace Darenth Park Hospital described in Box 8.

In this example, a significant element in the regional framework was the provision of practical help to local agencies with the implementation of good practice, in the form, for example, of special funding policies, a housing acquisition task force and a regional training initiative.

This training initiative adopted an explicit organisational development focus, characterised as the *Training for service development* model (See Box 10). This was designed to provide most support to people developing innovative service models, while treating the actual choices made as steps in a process of learning rather than alternatives of equal merit. The training strategy adopted had both organisational and individual components.

Training Strategy

The most important areas of service development identified as a training need are likely to include residential services (especially where hospitals are closing), day services (where the traditional day centre model is increasingly coming under criticism) and family

BOX 10 'Training for service development'

The starting point for the 'Training for service development' model was understanding that service development is a learning process, rather than the rigid implementation of a prepared plan. Five ground rules were identified:

1 Accept that service models will change as ideas and experience grow.

2 Make a modest start with service models that are as innovative as planners are happy with.

3 Plan in terms of resources not buildings so plans can be improved on the way.

4 Try some development at 'the leading edge' to get knowledge and experience of the best.

5 Review ideas and practise 'little and often'.

Within this framework, training needed to use the methods of organisational development if it was to be effective. This meant

1 **A bias for action**

Concentrating on showing by example rather than arguing philosophy in the abstract, because this was a more effective way of changing attitudes and because it allowed a start to be made before a great debate was won.

2 **Backing winners**

Working mainly with people already trying to develop innovative services, rather than using up resources trying to convince people stuck in providing institutions. This was not only the best use of resources but also helped produce tangible achievements fastest.

3 **Learning from real-life experiences**

Bridging the planning and delivery of services to make planners and managers more responsive to the effects of their decisions on the lifestyle of the people served. This meant working with teams of people on real-life tasks over relatively long periods, rather than providing short courses or 'hit-and-run' consultancy.

4 **Building bridges**

Adopting a multi-disciplinary, multi-agency focus to ensure that teamwork and cooperation are high on the agenda and are practised through work on the training project.

support services such as community mental handicap teams. In South East Thames region, the first priority was the development of staffed housing for people with learning disabilities. Where they had any clear plans, most district health authorities in the early years envisaged providing campus or hospital-type services. There was, however, widespread interest among operational managers and local staff in providing supported housing for people irrespective of their level of disability.

The training intervention was a course called 'Developing staffed housing for mentally handicapped people', which brought together multidisciplinary teams of people working locally who were already committed to this model. Over a period of eighteen months, teams met every six to eight weeks for a two-day workshop which addressed the practical issues of thinking through the details of the project each team was working on and how it would be implemented. The workshops included a decision-making framework for the planning process, presentations on lessons from model services, time for each team to work on its own project and consultancy from course organisers and external resources to help with specific problems. Evaluation after two years showed substantially more staffed housing in South East Thames than in the other similar regions and suggested that the course had played a central role in achieving this (Mansell 1989).

A similar project focused on helping local services to resettle a small number of people who, as well as severe or profound learning disabilities, had such serious challenging behaviour that institutional care had been seen as the only option. This provided local service agencies with help to set up staffed houses (typically for up to four people, one of whom came into the target group) and the carefully planned programme of care required. The help was provided by a Special Development Team and backed up with financial incentives. This combination proved relatively successful at setting up community-based services for people widely believed to 'need' institutional care and has produced substantially better results for clients than either 'old' hospitals or 'special units' (Mansell and Beasley, 1990).

Both these examples illustrate 'training for service development' as an integral part of the planning and management of new services, in which the trainers are playing a much broader role than is usually the case. These are also examples of strategic management intervention by a regional authority (although it is perfectly possible to imagine the staffed housing course working in a social services department or district health authority with a number of housing projects).

Direct care staff

A further task is the organisation of training in the traditional sense; the planning and delivery of training to equip direct care staff (some of whom will have worked in institutional services, many of whom will have no experience) with the skills and knowledge required. Delivery of the training required has to happen at local level because of the numbers involved and the importance of establishing firm connections between staff education and local management practice.

For induction and in-service training there are clear opportunities to put together appropriate programmes which emphasise hands-on skills of the kind needed in community services. A series of video-assisted packages, designed to enable local trainers to run their own training but to draw on good practical illustrations, was produced for the work in South East Thames under the general title 'Bringing People Back Home'. This was backed up by a trainers' development programme, a one-year course accredited by the Institute of Training and Development which includes a practical training project in the students' own service. The advent of the framework of National Vocational Qualifications opens up the prospect of constructing modular, accredited training based on materials and approaches like this to create a worthwhile career path for basic-grade staff.

Community services will also require leadership which combines some of the skills of mental handicap nursing and residential social work, but tailored to the new pattern of more individualised services in the community. In the South East Thames example, this has been tackled by setting up one of the first schemes of shared qualifying training in the country and by exercises to develop local training strategies.

These local initiatives are becoming all the more important given the decline in traditional qualifying training arrangements and current trends towards disinvestment in training by health and local authorities.

One other comment about training for front-line staff is worth making on the basis of the South East Thames experience. Much effort was invested early on in training in the philosophy of new services and particularly in normalisation. This was undoubtedly important in getting across a body of new ideas to many people, but later experience has shown that, where it was not backed up with practical training that demonstrates how to operationalise the principles in everyday work with clients, services have remained vulnerable to breakdown and have found it hard to provide appropriate support to service users.

In two areas more specialised training needs to be provided for key individuals. First, the managers and professionals leading the development of community care need training. Members and chief officers can create a climate in which innovation can flourish but the successful development of high-quality services requires committed and dynamic operational managers who know something about what is feasible in the new services they are building. Often the most senior people in their agency having responsibility for one client group, it is these people who must think through the detailed issues of principle and the myriad problems of implementation to produce new and relatively untried service models which assure high standards of care. The first example of a course tailored to meet this need was the MA in Applied Psychology of Mental Handicap Services at Kent, now modularised and linked with the MBA programme of the Canterbury Business School.

The second specialised area of training is that of 'special needs'. Providing good services for people who, in addition to their learning difficulty, have sensory handicaps or challenging behaviour, or psychiatric illness or chronic health problems, is a skilled task which will not adequately be fulfilled by some kind of generic 'community carer'. In South East Thames, one example of trying to meet this need is a Diploma course in work with people who have challenging behaviour. However such training is organised, it is important that it produces effective hands-on work.

Continuing growth and development

The development of high-quality, small-scale services to replace institutions is not a one-off transfer from one model of care to another; everywhere these kinds of services have been developed in the community they have faced problems of fragility and vulnerability because of their newness. Consolidation and continuing development are essential if the opportunities created by community care are to be realised. For example, as whole systems of housing projects are developed, new problems arise of how to sustain them without imposing the kind of uniformity that characterises institutions (but also without having them disintegrate by being left to 'sink or swim').

Many local service agencies in South East Thames face these problems now; the pioneers who set up community services have moved on and new challenges have to be faced. Where this is happening, local managers are adopting a systems perspective to build a resilient infrastructure which can sustain high-quality services. In Camberwell, for example, local managers are working with regional consultants to refocus the residential service on client experience; in Canterbury this is being done under the rubric of 'Total Quality Management' and similar work is going on in Lewisham and North Southwark. In each case, early emphasis on philosophy is being balanced by attention to how these ideas are put into practice in the day-to-day work of staff with clients and the implications of this in terms of staff recruitment, training and management. In many respects, therefore, this work continues to use *training for service development* as a model for addressing the training task.

3.7 Learning for quality

The extent to which the work of public authorities enables people with learning disabilities to live fulfilling and valued lives in the community is the principal measure of quality for these services. As Section 3.2 suggests, what this means in practice is continually being redefined as the potential contribution of people with learning disabilities is more fully recognised and as providers become more skilled in offering the support necessary for this contribution to be realised. More is also being learnt about the structures and processes required to promote these positive outcomes.

For enabling public authorities, the concern here is with outcomes for people with learning disabilities in the *population* for which they accept responsibility. This population orientation means paying attention to whether available resources are being deployed fairly to meet priority needs; whether the opportunities and services being developed are sensitive to differences – for example, in ethnicity; and whether this provision is accessible.

For provider agencies – whether the public authorities themselves or other organisations – the primary interest will be in outcomes for the *individuals* they have been contracted to serve.

In recent years there has been growing interest in the pursuit of quality in both local and health authorities. *Caring for People* and the subsequent Social Services Select Committee commentary have drawn attention to the importance of quality assurance procedures and 'arms length' inspection (House of Commons, 1990). The evidence from the King's Fund programme is that these welcome developments should reinforce a primary commitment to quality in the policy, management and review processes of the enabling and providing agencies. They can certainly not substitute for it.

Towards a 'quality culture'

Successful agencies are likely to be those where there is a 'quality culture'. This means that concern with quality is *intrinsic* to policy-making, planning, financing, managing and delivering services. As a result, people at all levels inside and outside the system of provision continually ask – and seek to answer – the question 'How will this decision or action contribute to positive outcomes for people with learning disabilities and their families?'.

As this questioning approach implies, a key feature of the quality culture is widespread involvement in learning and problem-solving. Effective managers appreciate the importance of learning from both achievements and disappointments. Enough is known about the factors which contribute to good services for managers to check whether these are present locally, and whether they are being sustained (see Section 3.4). Reflecting on achievements and sharing lessons with others can be helpful ways of encouraging further progress.

Equally, as O'Brien argues persuasively, there is a great deal to be learnt by 'embracing ignorance, error and fallibility' – by being 'thoughtful and decisive about what we don't know; what goes wrong as we act on our commitments; and where the limits to our abilities are' (1987). Promoting community integration is always an uncertain process which cannot be fully controlled by providing agencies. As a result, there is a need for continuing attention to outcome-oriented problem-solving in which people share in finding better ways forward. These learning processes are likely to be further enhanced where a variety of different perspectives – users of services, relatives, providers, purchasers, independent evaluators – are mobilised in assessing progress and seeking new solutions. If this is to be effective, agency staff will need to be open to criticism and willing to work with the tensions and conflicts this pluralism necessarily involves.

Systematic safeguards

The vulnerability of many people with learning disabilities has led the best public authorities to consider the development of multi-faceted systems and procedures for pursuing quality (See, for example, All Wales Advisory Panel, 1989). It is important for these arrangements to operate at all levels of the service system. They must also be multidimensional, with components which are internal to the enabling and provider agencies; components which start from user and community experience and – in doing so – involve ordinary people from outside the 'system'; and components which make use of independent authority and expertise. They need to include some procedures to provide 'back-up' protection for people when other things go wrong.

Figure 12 **Pursuing quality systematically**

<table>
<tr><th>Internal to enabling authority</th><th>Internal to provider agencies</th><th>Involving users and community</th><th>Established independently</th></tr>
<tr><td colspan="4">AUTHORITY-WIDE</td></tr>
<tr><td>• Positive and equitable policies for people with learning disabilities
• Culture of commitment to quality, openness and learning how to do better
• Member scrutiny of performance
• Planning, management and review processes supporting policy objectives
• Investment in skilled service design and development
• Contracting of services based on standards and performance monitoring
• Complementary investments in staff training, information systems and evaluation</td><td>• Commitment of generic providers to including people with learning disabilities
• As with enabling authorities:
-positive policies and appropriate imagery
-quality culture
-supportive management
-skilled development
-staff training</td><td>• Forums for policy dialogue with user relative and community representatives
• Development of voluntary associations engaged in collective advocacy for and with user interests
• Service review processes involving users and relatives</td><td>National inspectorates
External review
Regulatory arrangements and 'arms length' local inspection
Voluntary accreditation
Evaluation research</td></tr>
<tr><td colspan="4">LOCAL</td></tr>
<tr><td>• Emphasis on locality as the focus for comprehensive provision
• Decentralised problem-solving
• Information and accessible entry to opportunities and services
• Active case finding</td><td>• Operational policies specifying goals, working arrangements and relationships with other providers
• Clear job descriptions and staff procedures
• Positive monitoring of performance</td><td>• User and relative participation in management committees, advisory groups and review teams for particular services</td><td>• As above
• Independent advice and advocacy agencies</td></tr>
<tr><td colspan="4">INDIVIDUAL</td></tr>
<tr><td>• Individual service planning
• Case management
• Monitoring of individual provision</td><td>• Quality assurance programmes
• Supports to community integration
• Systematic efforts to improve functional abilities</td><td>• Self and citizen advocacy
• Circles of support
• Complaints procedures</td><td>• Independent case management and brokerage arrangements</td></tr>
</table>

BOX 11 Birmingham City Council
Checklist for community service development and review

Through its Community Care Special Action Group, members of Birmingham City Council agreed a simple checklist to apply to all proposals for developing services for people with disabilities. It included the following questions:

- Does this service encourage participation by people with special needs alongside people who are not disabled?
- Does this service recognise the rights and responsibilities of its users?
- Are the consumer's needs determined on an individual basis and in full consultation with him/her?
- Is real, informed choice offered to users?
- Does the service offer independent advocacy (including translation facilities) for those who cannot speak for themselves?
- Are the (possibly different) needs of the consumer's carers given proper consideration?
- Does the service provide a positive image or are people likely to be stigmatised by its use?
- Is the service equally relevant and accessible to all irrespective of race, culture, gender or disability?

Figure 12 summarises key components of a systematic approach to pursuing quality by level and dimension.

Multi-faceted approaches which embrace most of the components identified here are more fully developed in the United States than the UK. This reflects both the greater American experience of a 'mixed economy' of providers and the fact that recognition of individual rights and an attempt to balance different types of power are built in to the US Constitution. Michigan's Macomb-Oakland Regional Centre (see Box 1) is an example of an organisation which has developed quality safeguards which are central to sustaining its reputation for high quality services.

The agencies which the programme has worked with in Britain are typically at a rather earlier stage, with some of the components identified in Figure 12 more developed than others. Looking across different authorities, there are concrete examples of nearly all these arrangements, however.

Internal safeguards

Many of the components which are internal to the enabling and providing agencies (columns 1 and 2) have already been considered in the preceding Sections. Member level commitment to positive policies – as in the Birmingham example, see Box 11 – and managerial leadership on quality – as in Somerset – are both important here. So is the commitment of providing agencies to promoting the participation of people with learning disabilities in ordinary forms of education, employment and leisure. Again, Birmingham and Humberside are examples of public authorities which have made this kind of commitment, as are agencies in the independent sector like Barnardos and the Southwark Consortium.

In addition, both service purchasers and providers are increasingly seeking to introduce internal quality assurance methods. The Independent Development Council's guidance on 'Pursuing Quality' has proved influential here (1986).

Following the IDC lead, both the North Western and South East Thames regions have developed and disseminated systematic procedures. A recent illustration of what introducing methods like these involves at the local level is provided by the Grimsby case study (Box 12). Elsewhere, there have been some attempts to develop – and use – more prescriptive evaluation tools. In Wales, for example, a simple

BOX 12 Improving day-time opportunities in Grimsby

Following Humberside-wide commitment to a principled 'Plan for Change, 2000', social services managers in the Grimsby district have taken the lead in making quality assurance procedures intrinsic to local service development. They have concentrated on the provision of day-time opportunities for adults, where the social services department has lead responsibility.

Senior managers appointed an inter-agency group with representation from social services, adult education, the NHS, parents and the self-advocacy group facilitator to steer the development work. Their quality assurance strategy has combined widespread participation in planning improvements with selective studies of priority issues, using a variety of illuminating methods.

The main vehicle for participation has been a regular workshop involving service users, parents, care staff, and managers from relevant public and voluntary agencies.

These workshops have been used to:

- debate and clarify service goals in the light of the aspirations and experiences of users;
- identify priority areas for review; and
- consider the action necessary to make improvements.

There has also been wider consultation with interested parties on proposals for change.

The study methods used reflect the steering group's wish to get 'different angles' on the quality of existing opportunities. To date:

- two staff from other parts of the service have surveyed satisfaction with current provision through semi-structured interviews with a sample of users, parents and delivery staff;
- members of the steering group looked in detail at the lives and experiences of a small cross-section of users, including some with the most severe disabilities;

BOX 12 *continued*

- a manager reviewed records from individual planning meetings, paying particular attention to the goals being set and progress achieved;
- staff and parents together developed a framework for 'peer review' visits to different settings providing daytime opportunities.

Over two years, investment in this combination of activities has provided managers and consumer representatives with a useful 'balance sheet' on the strengths and weaknesses in current provision. Because of the way that it was generated, it has also given both impetus and an informed mandate for planning improvements.

Strengths

- Positive approach to planning with and for individuals
- Growing opportunities for people to use community resources
- Managerial commitment across agencies to improve quality

Weaknesses

- Poor links between home and day-time experiences
- Narrow range of personal goals set in individual planning meetings
- Continuing dominance of 'segregated' experiences

Planned action

- Improved communication between staff, relatives and users
- More staff emphasis on skills useful in integrated settings
- Support for less protective attitudes
- Development of mainstream educational and vocational opportunities
- Encouragement to self-advocacy

More generally, these activities provided the basis for a new forward planning process which started from user experiences and demonstrated an approach to quality review which can be applied across the full range of local services.

'standards matrix' has been employed in service reviews. PASS – a more detailed methodology for assessing community integration – has been used episodically by some agencies, for example the Children's Society. In the United States, where there is much more interest in external accreditation, the Accreditation Councils have produced comprehensive standards and program evaluation procedures.

Involving users, carers and advocates

Moving to the third column of Figure 11, preceding Sections have already examined the critical importance of the participation both of people with learning disabilities and their unpaid care-givers in the planning and delivery of local services. This is equally true in the pursuit of quality. Put most simply, people with learning disabilities have the only direct experience of the impact of services. Their relatives generally have known them better and longer than any providers.

Section 3.3 reports how people, their relatives and advocates have been involved in the different activities identified in Column 3. In the Welsh counties and Nebraska this has taken place at authority-wide level, and in Camden, Richmond and Southwark it has related to particular services and individuals.

Two points drawn from the American experience are relevant here. In the United States, federal legislation has given both weight and opportunities to collective advocacy by encouraging the creation of disability councils to advise the State agencies. These resemble Community Health Councils, but have a more specific brief. Second, the federal government has required the development of independent local agencies to protect service users' rights. This covers investigation of complaints and professional advocacy. The Social Services Select Committee argues that both these arrangements might usefully be incorporated into British quality safeguards.

Independent safeguards

The fourth column in Figure 12 identifies other independent contributions to pursuing quality at different levels. There are, of course, a number of national agencies which have inspection, advice or development as important functions. They include the Education and

Social Services Inspectorates, Mental Health Act Commission and National Development Team.

Implementation of the 'Caring for People' proposals in particular could offer the SSI an enhanced role in reviewing community care plans. This could include assessment of local quality assurance systems and complaints procedures – although it is less clear what incentives the reviewers will be able to offer for improved performance.

A potentially significant new requirement of the *NHS and Community Care Act* 1991 is for local authorities to establish 'arms length' (that is, quasi-independent) inspection units by 1 April 1991. These units will initially have inspection responsibilities across the providers of residential care as well as registration responsibilities in the independent sector, with related responsibilities arising from the *Children Act,* 1989. The Department of Health is also to provide guidance on standards for homes for people with a 'substantial learning difficulty'.

In due course these units will also – subject to constraints on resources and skills – be able to assist in the local development of contract monitoring and quality assurance programmes, and widen their attention to domiciliary and other services. However, the initial challenge to the enabling authorities will be to establish the wider conditions necessary for inspection units to make an effective contribution to improving the quality of life for people using residential services.

On a more general point – and borrowing concepts from another kind of large-scale change process – effective authorities have recognised that in 'learning for quality', the 'perestroika' represented by increasing diversity in opportunities and services, needs to be complemented by an active 'glasnost': that is, a real investment in opening up performance to the scrutiny of different parties, while protecting the dignity and privacy of service users. This means taking a critical look at the links between outcomes and activities throughout the service system. It also means using a variety of methods in order to minimise the risk of quality failures.

4

Implications for national policy

4 Implications for national policy

This report distils recent experience to show how public authorities can use the changing policy context of the early 1990s to assist people with learning disabilities in living more fulfilling lives. It aims to show how local strategies can make use of the opportunities offered by developments in current social policy. In doing so, it offers a positive vision of the part that public authorities can play in enabling community integration.

Looking across the fields of education, housing, social security, health and local government, it is clear that the wider policy climate is far from positive. In practice, public authorities face major challenges if they are to build on the limited achievements of the 1980s in a way that extends better life chances and choices to everyone with a learning disability during the next decade.

Even in the community care field, it is not yet certain whether the provisions of the *Children Act* 1989, the *NHS and Community Care Act* 1990 and other major changes will help local agencies transform existing provision to better meet the needs of people with learning disabilities. In particular, much of the thrust of 'Caring for People' was aimed at better supporting frail elderly people in the community. The distinctive needs of people with learning disabilities for long-term (often life-long) support, and for access to mainstream housing and work opportunities have not been explicitly recognised in national policy.

The King's Fund programme has involved work with governments in Wales, Arizona, and the Australian State of Victoria, as well as a wide range of authorities at a more local level. Drawing from this experience, it is possible to identify a number of issues which national policies need to address in order to provide a better framework for local action.

A positive role for government

Government cannot itself ensure that people with learning disabilities have the support necessary to make and sustain the complex pattern of informal relationships which constitute 'community integration'. Nor is it likely that 'top down' prescription of particular patterns of provision will be successfully implemented.

However, Government can establish conditions which give direction, incentives and support to appropriate local action. It can also modify these conditions in the light of experience.

More specifically, the examples of Wales and the State of Victoria demonstrate that government has a vital part to play in promoting principled change. This role has seven dimensions:

- Government can inspire local action through the clarity of the values and vision which inform national policies and the ways in which they are implemented.
- Using this vision, inter-departmental coordination at the centre can demonstrate – and stimulate – the importance of multi-agency collaboration at the periphery.
- Government can define individual entitlements for income support, assessment services and equal opportunities.
- Government can identify and prescribe responsibilities for different types of authority locally.
- Government can define the resource context for local action, and provide financial incentives for positive change.
- Government can promote change directly by sponsoring innovations; creating development agencies; establishing training arrangements; supporting voluntary action and commissioning evaluation research.
- Government can develop monitoring arrangements to reinforce local action and inform further policy making.

Given this interpretation of government's contribution to policy development and the issues raised by the analysis of local experience presented in this report, what could government now do to provide a more appropriate national policy framework?

A possible answer is summarised in the following letter:

The Right Honourable William Waldegrave PC, MP
Secretary of State for Health
Department of Health
Richmond House
79 Whitehall
LONDON SW1A 2NS

Dear Secretary of State,

Enabling people with learning disabilities to lead an ordinary life

We understand that Ministers and officials in your Department are currently preparing a fresh statement of policies on community care for people with learning disabilities. Coming twenty years after the 'Better Services' White Paper, and in the new context created by 'Caring for People', we believe this is an opportune time for fresh national leadership to ensure that the momentum behind developing decent quality opportunities and services for people with learning disabilities is sustained and increased in the 1990s.

As you know, the King's Fund has taken a continuing interest in this area. This was originally in response to the evident neglect of people with learning disabilities in public policy. More recently, the Fund has been involved in promoting the development of good community based services through our 'an ordinary life' initiative.

We are ourselves just writing up the King's Fund College's four year programme of action research on the ways in which health and local authorities are seeking to achieve large scale change in these services. With support from the Joseph Rowntree and Mental Health Foundations, the College has had an opportunity to work closely with twenty sets of authorities in different parts of the country as well as to meet local leaders from a variety of others.

Our report on this work, *Enabling Community Integration,* is addressed primarily to members and senior managers in these authorities as they grapple with current challenges. We believe, however, that what we have seen of both the successes and the weaknesses of different local strategies has significant implications for what is now required from national policies. We also know from what we have seen in Wales and from international experience that government can do a lot to establish the conditions for effective local action.

Our aim here is to identify a framework of key issues which should inform more detailed policy-making, and – at the same time – criteria against which specific policies might be judged.

Our own local work supports the view that a new national policy initiative is needed. Recent reports from the Audit Commission, your own National Development Team and the Independent Development Council for People with Mental Handicap have all suggested that the modest progress made towards better local services in the 1980s may now be stagnating, while the majority of people with learning disabilities and their families continue to receive poor quality or inadequate support.

It is true that more services are required almost everywhere to address unmet needs, which are often partly obscured by the willingness of parents to make enormous efforts to provide lifelong support themselves. It is also true, however, that much of the current investment in these services is poorly used, at least in part because of past weaknesses in national policies.

Against this background, our work suggests that a new national policy framework should include at least the following elements:

1 A clear commitment to enabling people with learning disabilities to enjoy a full life in the community

Sustained progress at local level is most likely when it is guided by a clear sense of purpose. The Welsh Office has been unequivocal in its efforts to ensure that all aspects of the All Wales Strategy are informed by the basic principles, which were developed in 1983. In the Australian State of Victoria, similar principles have been built into legislation (we attach an excerpt from the *Intellectually Disabled Persons' Services Act* 1986).

For the United Kingdom, an appropriate statement might build on the aims specified in *Caring for People,* and reinforce the idea that local services should:

- enable children to grow up in families;
- enable adults to have homes of their own;

- provide mainstream educational, work and leisure opportunities;
- help communities to integrate people with learning disabilities into normal patterns of life in ways which are appropriate to their cultural and ethnic backgrounds.

2 Inter-departmental collaboration

It follows, of course, that the development of opportunities for people with learning disabilities to participate in the mainstream of life cannot be primarily a matter for health and social services. This is true both nationally and locally. Instead, coordinated efforts across departments are required which include contributions:

- from education in promoting greater integration of children with learning disabilities in mainstream education;
- from employment to help create opportunities for real jobs;
- from environment in promoting the development of appropriate housing options;
- from social security in providing income support arrangement that encourage community involvement, particularly through work.

If the Department of Health is 'lead agency' in this national strategy, it will be important that it demonstrates its enabling role in mobilising and linking these wider contributions.

3 Clear allocation of responsibilities

At the same time, the Department of Health has a particular responsibility for identifying clearly the tasks which local authorities, the NHS and other agencies need to address in maximising progress and ensuring the Department's own monitoring arrangements – for example, for reviewing community care plans – promote the integration of local agencies' approaches. At a time of significant upheaval in local provision, the Department should also seek to identify and protect the resources necessary to undertake these tasks.

4 **Entitlements**
In Britain, both the 1981 Education Act and the 1986 Disabled Persons Act – particularly when fully implemented – provide people with learning disabilities and their families with important new entitlements to individualised assessment and support. These have recently been augmented by the provisions of the Children Act 1989 and some of the expectations generated by 'Caring for People'. In the 1990s, national policies should work to ensure that these advances are fully implemented at local level, and that they are linked to well-coordinated efforts to extend ordinary living opportunities to people with learning disabilities and their families.

5 **User participation**
The national government could work to promote user involvement in service design and monitoring by supporting self-advocacy organisations directly, and by making user participation a condition for central government support for local policies and plans.

6 **Commitment to resettlement**
The government's commitment to resettling the 27,000 people with learning disabilities in long-stay NHS institutions needs to be restated in the light of the new context created by the *NHS and Community Care Act* 1990. In particular, the mechanisms needed for 'bridging' the costs of the transition from hospital care to community living should be made clear, along with arrangements for redeploying staff from the NHS.

7 **Development initiatives**
Any national strategy needs to include a capacity to support and encourage change through demonstration projects and other initiatives. These might include efforts to develop better coordinated supports for families of children with learning disabilities, improved transition arrangements for disabled school leavers, more supported employment opportunities and imaginative supported housing arrangements. Informed change could also be supported by strengthening the capacity of the National Development Team to provide local advice, further evaluative research and more efforts to learn from international experience.

8 **Training**
All of the many initiatives presently underway to develop care management and the other staff competencies necessary for the implementation of the NHS and Community Care Act 1990 need to be tested for their relevance and application to services for people with learning disabilities. In addition, national workforce planning, training and retraining arrangements are required if appropriately skilled staff are to be available for a dispersed, locally-based service.

9 **Safeguarding quality**
Strategic development at national level should include monitoring of local performance, including the development of comparative indicators for performance locally. National standards will assume increasing importance as services continue to become more dispersed and localised.

For governments, as for leaders everywhere, the test of policy initiatives and service development will be in the improvements they bring to the lives of people with learning disabilities and their families. The extent to which national policy and its local implementation extends people's capacities and opportunities for leading fulfilling lives alongside their fellow citizens is the litmus paper for assessing success. Nationally and locally, the reality of people's experiences provides both the starting and the finishing point for policy and service development. Here, once again, the touchstone should remain the extent to which local services – and the national policies which shape them – help support people in their ability to live an ordinary life.

Yours sincerely,

David Towell
Virginia Beardshaw

Annex
National principles – the example of Victoria

Statement of principles

It is the intention of Parliament that in the administration of this Act and the provision, management, development and planning of services for intellectually disabled persons the following principles are to be given effect to:

(a) Intellectually disabled persons have the same right as other members of the community to services which support a reasonable quality of life;

(b) Every intellectually disabled person has a capacity for physical, social, emotional and intellectual development and a right to individualised educational and developmental opportunities and is entitled to exercise maximum control over every aspect of his or her life;

(c) The welfare of an intellectually disabled person is the first and paramount consideration;

(d) The needs of intellectually disabled persons are best met when the conditions of their everyday life are the same as, or as close as possible to, norms and patterns which are valued in the general community;

(e) Services should promote maximum physical and social integration through the participation of intellectually disabled persons in the life of the community;

(f) Services generally available to all members of the community should be adapted to ensure access by intellectually disabled persons and specialised supplementary services should be provided to the extent required to meet individual needs;

(g) Services to intellectually disabled persons should be provided in such a manner that an individual need not move out of his or her local community or travel inordinately long distances to receive the services needed;

(h) Services to intellectually disabled persons should be sufficiently flexible in structure and organisation to meet the varying needs of intellectually disabled persons in developing towards independence and to maximise the choices open to them;

(i) It is in the best interests of intellectually disabled persons and their families that no single organisation providing services to intellectually disabled persons exercise control over all or most aspects of an individual's life;

(j) It is the responsibility of the State of Victoria to plan, fund, ensure the provision of and evaluate services to intellectually disabled persons according to the principles stated herein;

(k) It is in the interests of intellectually disabled persons and their families for non-government organisations providing services to intellectually disabled persons to continue to play a significant role in direct service delivery;

(l) The State of Victoria must ensure that government and non-government organisations providing services to intellectually disabled persons are accountable for the extent to which the rights of intellectually disabled persons are advanced and service quality assured;

(m) Intellectually disabled persons have a legitimate and major role to play in planning and evaluating services;

(n) When some restriction on the rights or opportunities of an intellectually disabled person is necessary, the means chosen should be the least restrictive of the available alternatives having regard to all the circumstances.

Source: State of Victoria, Australia, 1986.

Appendix
The King's Fund College development programme 1987-1990

Background

During the 1980s there were major changes in philosophy and practice in services for people with learning disabilities and their families, best expressed in the aspiration to provide the support required for *an ordinary life* in the community. These trends were reflected in the flowering of innovative services – often quite small in scale – which began to give concrete meaning to the emerging visions of community living.

Partly because of these trends but also because of new incentives, notably the 'Care in the Community' arrangements in England and the 'All Wales Strategy', this pattern of incremental growth began to be overtaken in the mid-80s by pressures for larger-scale and more rapid change. Both the Joseph Rowntree and Mental Health Foundations recognised that if the best of the available thinking about community-based services could inform these radical strategies, the second half of the 1980s could bring significant improvements in services for people with learning disabilities more generally.

It was also recognised however, not least from the influential 1985 report of the House of Commons Social Services Committee, that the local and health authorities were commonly failing to establish the optimum strategic framework for promoting the transition to community-based services. Many of the better services were partial, small-scale and well-resourced. While some lateral dissemination of similar approaches to other innovators could be expected, it appeared that the challenge of reproducing comprehensive local services on a large scale and in typical settings was raising qualitatively different problems.

Accordingly, on the basis of proposals submitted in 1986, the two Foundations commissioned the King's Fund College to undertake a four year action research programme designed to explore the conditions and strategies required to achieve large scale change. The Programme was to be distinctive in its focus on strategic issues and in making policy-makers and senior managers its main target.

Aims

Working directly with members and senior officers of local and health authorities and with representatives of user and community interests, the three main aims of the King's Fund College programme were to:

i assist agencies in designing and implementing concerted strategies for developing good quality opportunities and services for people with learning disabilities and their families;

ii draw and disseminate lessons from this work about how informed change can best be achieved;

iii identify implications for the national policies required to promote further improvements in opportunities and services in the 1990s.

This programme has tried to relate these aims to the changing national policy context, particularly the new challenges to field authorities flowing from the *Caring For People* and *Working for Patients* White Papers in 1989 and the *Children Act* 1989 and *NHS and Community Care Act* 1990.

Methods

The programme has combined intensive and extensive methods in a way designed to maximise its contribution to informed action.

First, the major investment has been in collaborative work with particular authorities and networks of local bodies to build and test better models of agency action:

- Large scale initiatives have been undertaken with the Regional Health Authority and County Councils in the South West of England, South East Thames RHA and Kent, Birmingham City Council, the Welsh Office and the Australian State of Victoria; work has also been undertaken with authorities in the North West and North West Thames RHAs and the State of Arizona.
- More local projects have included work with agencies in Belfast, Camden, Cleveland, Humberside, North West Surrey, Richmond and Southwark. There have also been opportunities to draw on the local work of the NDT including team visits to Burnley, Hereford and Worcester and Tower Hamlets.

Second, building on these intensive projects but also drawing on experience from other local initiatives, the programme has promoted a variety of theme-centred development work designed to clarify particular elements in good strategies. This has included attention to the leadership and enabling roles of public authorities, developing positive visions of community living, ways of strengthening user involvement, implementing assessment and case management arrangements, and planning and establishing systematic quality safeguards. As the national policy context has changed, opportunities have been sought to compare British experience with exemplary developments elsewhere, particularly in North America, with assistance from the Canadian Association for Community Living (and its G. Allan Roeher Institute), the Centre on Human Policy at Syracuse and Responsive Systems Associates from Atlanta.

Third, the programme has organised a continuing series of mutual aid development sets, meetings and more formal educational events both to help develop a network of visionary and effective local leaders and to share insights from the more intensive project and development work.

Fourth, publications and contributions to larger conferences have been used to disseminate lessons from these activities more widely. Working mainly through national bodies, particularly the Independent Development Council for People With Mental Handicap, the National Development Team and the All Wales Mental Handicap Strategy Advisory Panel, the programme has also sought opportunities to influence the development of national policies.

The programme has been led by David Towell and drawn on contributions from Ritchard Brazil, Nan Carle, Sheila Damon, Sholom Glouberman, Chris Heginbotham, Chris Horne and Ann James at the College, Virginia Beardshaw at the King's Fund Institute and Roger Blunden at the King's Fund Centre for Health Services Development.

Throughout the four years the programme team has benefited through meeting with an advisory group: Roger Blunden, Peter Bye, David Felce, Cynthia Fletcher, Tessa Jowell, Janet Lewis (Chair), Usha Prashar, Oliver Russell, Derek Thomas and Linda Ward.

Main Publications

The programme has aimed to report experience and disseminate lessons from this work both through publishing directly and through contributing to the publications of other agencies.

Direct publications:

Bracken, V., Brazil, R., Burton, M. and Towell, D. *Making Quality Central To The Development Of Community Care* London, King's Fund College Working Paper, 1987.

Brazil, R. (ed) *Making a Reality of Community Care: A response to Sir Roy Griffiths and his Review Team* London, King's Fund College Working Paper, 1987.

King's Fund Institute *Promoting Innovation in Community Care* London, King's Fund Institute Briefing Paper, 1987.

Brazil, R. 'Local authorities after Griffiths' *Social Work Today* 2 November, 1987.

Towell, D. (ed) *An Ordinary Life In Practice* London, King Edward's Hospital Fund, 1988.

Brazil, R., Etherington, S. and Georgiou, N. 'Innovations in joint planning and management' in Wistow, G. and Brooks, T. (eds) *Joint Planning and Joint Management* London, Royal Institute of Public Administration, 1988.

Towell, D. *From small-scale developments to mainstream provision for people with learning disabilities: A framework for planning promotional initiatives in support of large-scale change* London, King's Fund College Working Paper, 1988.

Towell, D. 'Victorian Community Care' *Social Services Insight* 30 August 1988.

Brazil, R. 'The role of voluntary agencies post Griffiths' *Social Services Insight* 22 November 1988.

Burton, M. *Australian Intellectual Disability Services – Experiments in Social Change* London, King's Fund College Working Paper, 1989.

Rochester, C. *Southwark Consortium 1984-1987* London, King's Fund College Working Paper, 1989.

Thomas, D. and Towell, D. 'Common Goals Across Oceans' *Health Services Journal* 4 January 1990.

Beardshaw, V. and Towell, D. *Assessment and Case Management: Implications for the implementation of 'Caring For People'* London, King's Fund Institute Briefing Paper, 1990.

Towell, D. *Users leading action in the health and social services* London, King's Fund College Working Paper, 1990.

Towell, D. 'Managing Strategic Change: A Principled Agenda for the 1990s' in Booth, T. (ed) *Better Lives* Sheffield University Social Services Monographs, 1990.

Heginbotham, C. (ed) *Caring For People: Local Strategies For Achieving Change In Community Services* London, King's Fund College, 1990.

Hawker, C. and Ritchie, P. *Contracting for Community Care: Strategies for Progress* London, King's Fund College, 1990.

Flynn, M. and Towell, D. *Partnership In The Struggle For Community Living* London, King's Fund College Working Paper, 1990.

Related publications to which Programme work has contributed:

South Western Regional Health Authority *Maintaining the Momentum in the Development of High Quality Community-Based Services for People with Mental Handicap in the South West* Bristol, SWRHA, 1987.

Melville, J. 'Breaking through mental handicap' *New Society* 8 January 1988.

Independent Development Council for People with Mental Handicap *Frameworks for Change* London, IDC, 1988.

National Development Team *The Development of a Contraction Strategy for the Brockhall/Calderstones Unit in Lancashire* London, NDT, 1988.

South Western Regional Health Authority *Services for People with Learning Difficulties: Strategic Policy Review* Bristol, SWRHA, 1988.

National Development Team *Services to people with learning difficulties living in Hereford and Worcester* London, NDT, 1989.

National Development Team *Towards A New Deal For People With Learning Difficulties In Tower Hamlets* London, NDT, 1989.

All Wales Advisory Panel *Proposals For The Independent Review Of*

Services For People With Mental Handicap In Wales Cardiff, The Welsh Office, 1989.

Independent Development Council for People with Mental Handicap *Cinderellas Again ? The impact of current national policies on opportunities and services available locally to people with learning difficulties and their families* London, IDC, 1990.

National Development Team *Promises To Keep – Making Community Care For People With A Mental Handicap And Their Families Into A Reality In The 1990s* (Evidence to the House of Commons Social Services Committee) London, NDT, 1990.

Winkler, F. *Who Protects The Consumer In Community Care? Lessons from North America London* Greater London Association of Community Health Councils, 1991.

All Wales Advisory Panel *Consumer Involvement And The All Wales Strategy* Cardiff, The Welsh Office, 1991.

Further Reading

As an aid to clarity in the text, we have used references sparingly – aiming only to identify the main sources for our examples and document empirical studies on which our analysis has drawn. However, our own thinking has been informed by a wider literature and some readers may wish to pursue issues we raise in more detail. Using the same framework as the report, this Appendix therefore offers a succinct guide to other work we have found helpful.

The current challenge

Changing aspirations about the opportunities and services required to support people with learning disabilities are well reflected in the series of King's Fund 'an ordinary life' publications which began with *An Ordinary Life: comprehensive locally-based residential services for mentally handicapped people* (London, King Edward's Hospital Fund, 1980) and progressed through *An Ordinary Working Life: vocational services for people with mental handicap* (1986), *Facing the challenge: an ordinary life for people with learning difficulties and challenging behaviour* (1987), *Ties and Connections: An ordinary community life for people with learning difficulties* (1988) and the overview volume edited by David Towell *An Ordinary Life In Practice* (1988). This and Ann Shearer's *Building Community with people with mental handicap, their families and friends* (London, King Edward's Hospital Fund, 1986) also describe a sample of the innovative small-scale services developed during the 1980s which increasingly demonstrated what the 'an ordinary life' principles mean in practice.

The current state of services and the extent to which these innovations are impacting on the lives of the majority of people with learning disabilities can be judged from a series of recent studies and reports. By far the most detailed is the six volume *Surveys of Disabilities In Great Britain* produced by the Office of Population Censuses and Surveys (London, HMSO, 1989). More selectively, the Audit Commission in its *Developing Community Care For Adults With A Mental Handicap* (London, HMSO, 1989) analyses the challenges and constraints facing local authorities in developing services for adults, the National Development Team draws on its local visits to identify key issues in both adult and children's services, the former in *Promises To Keep – Making Community Care For People With Mental Handicap And Their Families Into A Reality In The 1990s* (London, NDT, 1990), the latter in *Current Issues In Children's Services* (London, NDT, 1991); and the Independent Development Council for People with Mental Handicap offers a wider analysis in *Cinderellas Again? The impact of current national policies on opportunities and services available locally to people with learning difficulties and their families* (London, IDC, 1990).

In addition, the continuing series of National Development Team reports on visits to particular authorities provide an informative guide to the strengths and weaknesses in local services across England.

Leading the enabling public authorities

In responding to these challenges, we have suggested the importance of public authorities developing a positive understanding of their *enabling* role. Our own thinking here has been stimulated by an influential analysis of the changes this requires provided by John Stewart and Gerry Slater in *From Local Administration to Community Government* (London, Fabian Society, 1988), itself a contribution to the burgeoning strand of publications on local government, perhaps most usefully represented by Rodney Brooke's *Managing the Enabling Authority* (Harlow, Longman, 1989). Our understanding of strategic management in this context has drawn heavily on the work of our late colleague Tom Evans, most succinctly summarised in his essay on 'Strategic response to environmental turbulence' published in Stocking B. (ed) *In Dreams Begins Responsibility* (London, King Edward's Hospital Fund, 1987). These ideas are further developed, with particular reference to health services management in two further collections: Parston, G (ed) *Managers as Strategists* (London, King Edward's Hospital Fund, 1986) and Carle, N. (ed) *Managing For Health Result* (London, King Edward's Hospital Fund, 1990). The idea of the leadership/management cycle is also developed more generally by John Kotter in *A Force For Change: How Leadership Differs From Management* (New York, MacMillan, 1990).

In relation to community care, this leadership needs to be expressed in inter-agency collaboration. A helpful framework for addressing collaborative issues is provided by Gerald Wistow and

Peter Whittingham in 'Policy and research into practice', one of several interesting papers in Stockford, D. (ed) *Integrating Care Systems: practical perspectives* (Harlow, Longman, 1988). The Camden and Southwark examples of local collaboration are analysed further by Ritchard Brazil, Stuart Etherington and Nick Georgiou in 'Innovations in Joint Planning and Joint Management' in Wistow, G and Brooks, T (eds) *Joint Planning and Joint Management* (London, Royal Institute of Public Administration, 1988).

Further examples of the leadership contribution to large-scale change in services for people with learning disabilities are described in David Towell's *An Ordinary Life In Practice* (mentioned above) and a complementary collection on North American experience, Taylor, S.J., Bicklin, D and Knoll, J (eds) *Community Integration for People with Severe Disabilities* (New York, Teacher's College Press, 1987).

From Values to Vision

Building on the 'an ordinary life' philosophy, two major public sector initiatives in the early 1980s were influential in demonstrating the importance of planning strategic change on the basis of explicit principles. The All Wales Mental Handicap Strategy was based on principles set out in the *Report of the All Wales Working Party on Services for Mentally Handicapped People* (Cardiff, The Welsh Office, 1982) and the North Western Regional Health Authority strategy was shaped by their *Services for People with Mental Handicap: A Model District Service* (Manchester, NWRHA, 1983). The Association of Directors of Social Services' statement provides a contemporary example in similar form, *Community Care for People with a Mental Handicap/Learning Difficulty: Philosophy and Principles* (London, ADSS, 1990).

Participative approaches to helping people clarify values and principles, starting from the experiences of people with learning disabilities themselves, are exemplified by the workshop design in John O'Brien and Connie Lyle's *Framework for Accomplishment* (Decatur, Georgia, Responsive Systems Associates, 1987). A similar approach, with a focus on integrated learning opportunities, is reflected in 'The McGill Action Planning System: A Strategy for Building the Vision' (described in the *Journal of the Association for Persons with Severe Handicaps* 1989, Vol 4 No. 3 pp 205-215, in a paper by Vandercook, T., York, J. and Forest, M.).

A board game for use in these participative exercises with the apt title of *Outcomes* has been published by South East Thames Regional Health Authority (Bexhill-on-Sea, East Sussex, SETRHA, 1989).

A good summary of what these principles mean for people and services is contained in *Together – for an ordinary life* (Manchester, NWRHA, 1990). Most reports on National Development Team visits offer a similar vision, adapted to particular local needs, for example *Towards A New Deal For People With Learning Difficulties And Their Families In Tower Hamlets* (London, NDT, 1989).

The most useful comprehensive description of innovative local services which are aspiring to meet these principles is still Ann Shearer's *Building Community with people with mental handicap, their families and friends* (mentioned above). Also important in addressing these principles to the needs of a multi-racial society is Carol Baxter, Kamalijit Poonia, Linda Ward and Zenobia Nadirshaw's *Double Discrimination: Issues and Services for People with Learning Difficulties from Black and Ethnic Minority Communities* (London, King Edward's Hospital Fund, 1990).

Putting people first

A useful general review of issues affecting the influence of people with learning disabilities in shaping the opportunities they are offered is provided in *Consumer Involvement and the All Wales Strategy,* recently prepared by the All Wales Advisory Panel (Cardiff, The Welsh Office, 1991). The growth of self-advocacy is reflected in the production of a set of booklets for people with learning disabilities, *Learning About Self Advocacy* (London, Adept Press for the Campaign for People with Mental Handicap, 1988). The importance of informed support from other citizens is nicely captured in *The Power of Positive Linking* (Toronto, The G. Allan Roeher Institute, 1989). The importance of positive efforts to promote wider friendship networks is argued fully in *Ties and Connections: An Ordinary Community Life for people with learning difficulties,* (one of the King's Fund papers mentioned above) and well illustrated by Ann Richardson and Jane Ritchie in *Developing Friendships: Enabling people with learning difficulties to make and maintain friends* (London, Policy Studies Institute, 1989).

The ways in which the assessment and case management proposals in *Caring For People* could be used to ensure services are better related to individual needs are described in our own *Assessment and Case Management: Implications for the implementation of 'Caring for People'* (London, King's Fund Institute, 1990). An excellent approach to conceptualising need in the assessment process, based on the work of David Felce, is presented in another All Wales Advisory Panel report *Challenges and Responses: A report on services in support of adults with mental handicaps with exceptionally challenging behaviour, mental illness or who offend* (Cardiff, The Welsh Office, 1991). The use of this approach in 'personal futures planning' is nicely illustrated by Beth Mount and Kay Zwernik in their booklet *It's Never Too Early, It's Never Too Late* (St Paul, Minnesota, Metropolitan Council, 1988) although more accessible is Ann Brechin and John Swain's *Changing Relationships, Shared Action Planning with People with a Mental Handicap* (London, Harper and Row, 1987).

More strategic initiatives designed to make public services more responsive to their users include the Local Government Training Board's *Getting closer to the public* (Luton, LGTB, 1987). In the NHS, Liz Winn and Allison Quick describe a variety of innovations with similar intent in their *User Friendly Services: guidelines for managers of community health services* (London, King Fund's Centre, 1989) while, in relation to social services departments, Susie Croft and Peter Beresford have recently reported the results of a survey into *User involvement in the provision of social services* (York, Joseph Rowntree Foundation, 'Findings', 1990).

Again, the particular importance of addressing all these issues in ways sensitive to people from black and ethnic minority communities is highlighted in *Double Discrimination: Issues and Services for People with Learning Difficulties from Black and Ethnic Minority Communities* (referred to above).

New ways of working

A useful general analysis of the implications of recent legislative changes for the organisation of services for people with learning disabilities is provided in *Caring About Outcomes For People* (Manchester, NWRHA, 1990). A succinct attempt to distil lessons from North American experience is contained in Derek Thomas and David Towell's 'Common Goals Across Oceans' (*Health Services Journal* 4 January, 1990 pp 22-23).

Our own *Assessment and Case Management: Implications for the*

Implementation of 'Caring for People' (see above) reviews case management experience, while two papers helpfully detail current case management pilot projects, *Andover Case Management Project: Services for People with a Mental Handicap* (Winchester, Hampshire Social Services Department and Winchester Health Authority, 1990 – by Archer, R. and Robertson, G.) and *Case Management In Practice: Reflections on the Wakefield Case Management Project* (Leeds, Nuffield Institute for Health Services Studies, 1990 – by Richardson A. and Higgins, P.).

The limited British experience of purchase-of-service contracting in this field is reasonably summarised in the Department of Health's *Purchase of Service: Practice Guidance* (London, HMSO, 1991) although again, some important further issues on the provider side are highlighted in the National Council of Voluntary Organisations' *Contracts for Care: Issues for black and other ethnic minority voluntary groups* (London, NCVO, 1990).

The continuing importance of high quality service design is both argued and demonstrated by David Felce in 'Using behavioural principles in the development of effective housing services for adults with severe or profound mental handicaps' in Remington, R. (ed). *The Challenge of Severe Mental Handicaps* (Chichester, Wiley, 1991).

Managing transition

A general framework for considering the issues involved in managing large-scale transitions from institutional to community-based services is provided by David Towell, Su Kingsley and Tom McAusland in *Managing Psychiatric Services In Transition* (London, King's Fund College and NHSTA, 1989). This framework is illustrated in David Towell's account of the South West's experience 'Managing Strategic Change' in *An Ordinary Life in Practice* (referred to above). Nancy Korman and Howard Glennerster offer a fuller analysis of South East Thames' experience in *Hospital Closure: A political and economic study* (Milton Keynes, Open University Press, 1990) while the Independent Development Council provided a comparative analysis in *Framework for change: A review of Regional Health Authorities' strategies for promoting community-based services to people with learning difficulties* (London, IDC, 1988).

Along with the Korman and Glennerster work, research studies by Tim Booth, Ken Simons and Wendy Booth *Outward Bound: Relo-*

cation and Community Care for people with learning difficulties (Milton Keynes, Open University Press, 1990) and by the Personal Social Services Research Unit *Care In The Community: Lessons from a demonstration programme* (Canterbury, PSSRU, 1990) provide systematic evidence on the success of relocation programmes where the new services are well-designed. Drawing on this and other research, Alan Shiell has produced a short review of cost effectiveness studies, *The comparative costs of hospital and community residential care for people with a mental handicap* (York, Centre for Health Economics, 1990).

A number of National Development Team reports give particular attention to issues involved in managing contracting institutions, notably *The Development Of A Contraction Strategy For The Brockhall/ Calderstones Unit In Lancashire* (London, NDT, 1988).

Parallel and mainly American work on day services and supported employment is well represented by Solomon Jacobson's *Supported Employment Conversion Planning Workbook* (Baltimore, Maryland. The Kennedy Institute, 1987) and Tom Bellamy and his colleagues *Supported Employment: A Community Implementation Guide* (Baltimore, Maryland, Paul H. Brookes, 1988).

Developing staff

A good starting point for thinking about personnel and training issues, including workforce planning and employment policies is the NHS Training Authority paper *Services for People with Mental Handicap: Human Resource Issues* (Bristol, NHSTA, 1986). A general guide to training design issues in the caring services is Robin Douglas and Chris Payne's *Organising For Learning: Staff development strategies for residential and day services work* (London, National Institute for Social Work, 1988). With particular reference to services for people with learning disabilities, the Independent Development Council has recently produced its *Next Steps in staff training* (London, IDC, 1991).

Two of the most important South East Thames training initiatives are described more fully in Jim Mansell's *Staffed housing for people with mental handicaps & achieving widespread dissemination* (Bexhill, SETRHA, 1988) and Eric Emerson and his colleagues' *Developing services for people with severe learning difficulties and challenging behaviours* (Canterbury, Centre for the Applied Psychology of Social Care, 1987). The South East Thames work has also led to a comprehensive set of video-assisted training packages published as *Bringing People Back Home* (St Leonards, Outset Publishing, 1990).

Another excellent set of training resources are the three Open University courses *Mental Handicap: Patterns for Living* (P555), *Patterns for Living: Working Together* (P555M) and *Mental Handicap: Changing Perspectives* (K668), (Milton Keynes, Open University Department of Health and Social Welfare, 1986, 1989 and 1990), which between them are accessible to a wide range of audiences.

Learning for quality

The importance of making quality intrinsic to the planning, management and delivery of services is well argued in an influential Independent Development Council booklet *Pursuing Quality: How good are your local services for people with mental handicap?* (London, IDC, 1986). The need for modesty about our achievements, honesty about our mistakes and therefore commitment to learning from experience is nicely expressed in John O'Brien's 'Embracing Ignorance, Error and Fallibility; Competences for Leadership of Effective Services' in Taylor, S.J., Biklen, D, and Knoll, J (eds) *Community Integration for People with Severe Disabilities* (referenced above).

Two recent national reports have put the case for multi-level and multi-dimensional systems of quality safeguards, the All Wales Advisory Panel *Proposals for the Independent Review of Services for People with Mental Handicaps in Wales* (Cardiff, The Welsh Office, 1989) and the House of Commons Social Services Committee *Community Care: Quality* (London, HMSO, 1990). What this might involve in practice is well illustrated in Fidelma Winkler's *Who Protects The Consumer In Community Care?* (London, Greater London Association of Community Health Councils, 1991).

Useful guides to internal quality assurance procedures have been produced by the South East Thames region *What Matters Most: Quality Assurance Pack* (Bexhill, East Sussex, SETRHA, 1988) and the North Western region *A Guide To Quality Assessment* (Manchester, NWRHA, 1989). The best account of the logic underlying these procedures is John O'Brien and Connie Lyle's *Framework for Accomplishment* (referred to above), also reflected in the Welsh Office's paper on

Residential Services For Mentally Handicapped People In Wales: Standards Matrix (Cardiff, The Welsh Office, 1988). Much more detailed is the Accreditation Council on Services for People with Developmental Disabilities *Standards* (Landover, Maryland, ACDD, 1990).

Implications for national policies

Recent studies and reports which identify the current challenge to services are discussed above. Among these, the National Development Team's evidence to the House of Commons Social Services Committee *Promises To Keep – Making Community Care For People With Mental Handicap And Their Families Into A Reality In The 1990s* (London, NDT, 1990) is particularly helpful on national policy issues.

In the text we have drawn attention to the Welsh example of government efforts to provide a positive framework for local change in services for people with learning disabilities. A useful comparative account of the different approaches adopted by government in England, Scotland and Wales is still David Hunter and Gerald Wistow's *Community care in Britain: variations on a theme* (London, King Edward's Hospital Fund, 1987). Further afield, the positive role of government is well demonstrated in the Australian State of Victoria's *Intellectually Disabled Persons' Services Act,* 1986 (Melbourne, Victoria Government Printers Office) and the subsequent *Ten Year Plan For The Redevelopment Of Intellectual Disability Services* (Melbourne, Community Services Victoria, 1988).

Finally, recent accounts of progressive changes in opportunities and provision are brought together in Tim Booth's *Better Lives: Changing Services For People With Learning Difficulties* (University of Sheffield, Social Services Monographs, 1990) while an excellent picture of a better future is summarised in the Canadian Association for Community Living's *Community Living 2000* (Toronto, Ontario, CACL, 1987).

REFERENCES

Allen, P. and Scales, K. *Residents Rights* (Video and booklets) London, Newham District Psychology Department, 1990 .

All Wales Advisory Panel *Proposals for the Independent Review of Services for People with Mental Handicaps in Wales* Cardiff, The Welsh Office, 1989.

All Wales Advisory Panel *Challenges and Responses: A report on services in support of adults with mental handicaps with exceptionally challenging behaviour, mental illness or who offend* Cardiff, The Welsh Office, 1991b.

Association of Directors of Social Services *Community Care for People with a Mental Handicap/Learning Difficulty: Philosophy and Principles* London, ADSS, 1990.

Audit Commission *Developing Community Care for Adults With A Mental Handicap* London, HMSO, 1989.

Booth, T, Simons, K, and Booth W. *Outward Bound: Relocation and Community Care for people with learning difficulties* Milton Keynes, Open University Press, 1990.

Brechin, A. and Swain, J. *Changing Relationships. Shared Action Planning with People with a Mental Handicap* London, Harper and Row, 1987.

Department of Health *Caring for People: Policy Guidance* London, HMSO, 1990.

Department of Health *Purchase of Service: Practice Guidance* London, HMSO, 1991.

Devon County Council *Caring for the people of Devon in the 1990s* Exeter, Devon County Council Social Services, 1990.

Felce, D. 'Using behavioural principles in the development of effective housing services for adults with severe or profound mental handicaps' in Remington, R. (ed). *The Challenge of Severe Mental Handicaps* Chichester, Wiley, 1991.

Gathercole, C., McLean, T. and Whalley, D. Generating policy and action' in Towell, D. (ed) *An Ordinary Life In Practice* London, King Edward's Hospital Fund, 1988.

House of Commons Social Services Committee *Community Care: Quality* London, HMSO, July 1990.

Independent Development Council for People with Mental Handicap *Pursuing Quality* London, IDC, 1986.

Independent Development Council for People with Mental Handicap *Cinderellas Again? The impact of current national policies on opportunities and services available locally to people with learning difficulties and their families* London, IDC, 1990.

Jacobson, S G *Supported Employment Conversion Planning Workbook* Baltimore, Maryland, The Kennedy Institute, 1987.

King's Fund Centre *An Ordinary Life: comprehensive locally-based residential services for mentally handicapped people* London, King Edward's Hospital Fund, 1980.

Korman, N and Glennerster H. *Hospital Closure: A political and economic study* Milton Keynes, Open University Press, 1990 .

Mansell, J. Evaluation of training in the development of staffed housing for people with mental handicaps' *Mental Handicap Research* 1989 Vol 2, No. 2, pp 137-151.

Mansell, J. and Beasley, F. Severe mental handicap and problem behaviour: evaluating the transfer from institutions to community care' in Fraser, W.I. (ed) *Key Issues In Mental Retardation Research: Proceedings of the 8th Congress of the International Association for the Scientific Study of Mental Deficiency* London, Routledge, 1990.

McGrath, M. and Grant, G. *Supporting 'Needs-Led' Services: Implications for Planning and Management Systems* Bangor, Gwynedd, Centre for Social Policy Research, 1989.

Mount, B. and Zwernik, K. *It's Never Too Early, It's Never Too Late: A booklet about personal futures planning* St. Paul, Minnesota, Metropolitan Council, 1988.

National Development Team *Promises to Keep - Making Community Care for People With Mental Handicap And Their Families Into A Reality In The 1990s* London NDT, 1990.

National Development Team *Current Issues In Children's Services* London, NDT, 1991.

North Western Regional Health Authority *Caring About Outcomes For People* Manchester, NWRHA, 1990.

O'Brien, J. Embracing Ignorance, Error and Fallibility: Competences for Leadership of Effective Services' in Taylor, S. J., Bicklin, D. and Knoll, J. (eds) *Community Integration for People with Severe Disabilities* New York, Teachers College Press, 1987.

O'Brien, J. and Lyle, C. *Framework for Accomplishment* Decatur, Georgia, Responsive Systems Associates, 1987.

Office of Population Censuses and Surveys *Surveys of Disabilities In Great Britain* (6 volumes) London, HMSO, 1989.

Personal Social Services Research Unit *Care In The Community: Lessons from a demonstration programme* Canterbury, PSSRU, 1990

Provencale, G. 'Culturing Commitment' in Taylor, S., Biklen, D. and Knoll, J. (eds) *Community Integration for People with Severe Disabilities* New York, Teachers College Press, 1987.

Shiell, A *The comparative costs of hospital and community residential care for people with a mental handicap* University of York, Centre for Health Economics, 1990.

State of Victoria *Intellectually Disabled Persons' Services Act 1986* Melbourne, Victoria, Victoria Government Printing Office.

Towell, D. *An Ordinary Life in Practice* London, King Edward's Hospital Fund, 1988.

Welsh Office *Residential Services For Mentally Handicapped People In Wales: Standards Matrix* Cardiff, The Welsh Office, 1988.

Welsh Office, Social Services Inspectorate *'Still a small voice' Consumer involvement in all the Wales Strategy* Cardiff, Welsh Office, 1989.

Winkler, F. *Who Protects The Consumer In Community Care?* London, Greater London Association of Community Health Councils, 1991.

About this book

Enabling Community Integration is intended for senior managers and members of health and local authorities who are grappling with the challenges posed by the NHS and community care reforms to services for people with learning disabilities. Its subject is the ways in which public authorities can stimulate large scale change in services in order to achieve better lives for the people they serve. Based on a four-year action research programme supported by the Joseph Rowntree and Mental Health Foundations, *Enabling Community Integration* uses a wealth of recent examples from Britain and abroad to illustrate its approach to strategic change in public authorities. It continues the King's Fund's influential *An Ordinary Life* series.

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