KING'S FUND COLLEGE

ACHIEVING STRATEGIC CHANGE
IN OPPORTUNITIES AND SERVICES
FOR PEOPLE WITH LEARNING DIFFICULTIES

- A PRINCIPLED AGENDA FOR THE 1990s

David Towell

Introduction

Just ten years ago, the King's Fund published <u>An Ordinary</u> <u>Life</u>,[1] the working paper which became the first element in a continuing series of contributions to the development of community-based services for people with learning difficulties. We said then that our goal was to see people with learning difficulties 'in the mainstream of live, 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.' In terms which have since become more common, we tried to define our objectives by reference to the <u>outcomes</u> achieved in people's lives (Figure 1) rather than arguing for particularly facilities, professional inputs or agency responsibilities which still constituted the dominant currency of debate in 1980.

We have come a long way since then. Through the efforts of many energetic people locally, through the advocacy of other national agencies like People First, voluntary bodies in the IDC and the National Development Team, and through the stimulus of the Joseph Rowntree Memorial Trust research and development programme, the 'an ordinary life' philosophy has been taken up in a wide range of local initiatives. As my own review (<u>An Ordinary Life In Practice</u>, published in 1988)[2] reports, the component parts of the comprehensive opportunities and services of the future are becoming increasingly visible - if only on a small scale:

* 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 those which provide support for people with the most severe disabilities.

* They are there in the opportunities some people are finding for adult education and for real jobs.

* They are there in increasing support for leisure activities that other people enjoy.

* And most importantly, they are there in growing recognition of the importance of relationships, expressed for example in the circles of support where ordinary people make common cause with others at risk of serious disadvantage.

<u>The success of these initiatives should now give us the</u> <u>confidence we need to argue for a bold vision of community</u> <u>living for all people with disabilities as the target for the</u> <u>1990s.</u>

Figure 1.   POSITIVE OUTCOMES IN PEOPLE'S LIVES -
             THE OBJECTIVES OF COMMUNITY CARE

OUTCOMES FOR PEOPLE	HOME LIFE	EDUCATION/ OCCUPATION	LEISURE PURSUITS
Participating in the community	✓	✓	✓
Increasing competence	✓	✓	✓
Exercising individual choice	✓	✓	✓
Gaining self-esteem	✓	✓	✓
Sustaining and widening friendships	✓	✓	✓

However as we enter the new decade, we need to accept that we are still only at an early stage in the national transformation of opportunities and services. The pioneer community-based services have themselves been limited, for example in the extent to which they have sought to encourage choice for people with learning difficulties and widen their participation with non-disabled people in community activities. Even some of the best have remained insecure in the absence of strong support in the providing agencies. And the increased pace of change has produced pressure for quick results in some places which has undermined quality and weakened support for further change.

Moreover, despite this decade of effort, it is probably the case that the majority of people and their carers have so far seen little change. I recently led the NDT team which visited Tower Hamlets.3 Two images particularly stick in my mind from that visit. One is sitting in a group with five elderly women at a public meeting, each of whom had already been providing care for now adult children at home for thirty years or more, had no plan for what would happen to their son or daughter when this support was no longer available, but strongly suspected that after spending a life-time in the borough their son or daughter would be sent away to private residential care in the country once the public agencies accepted some responsibility. Equally moving was another public meeting where more than half those present were Bengali parents, mainly of younger children, many approaching desperation in their pleas for understanding and support in managing under very difficult conditions.

Although it is only a mile or two from the City of London and includes part of the Docklands development, Tower Hamlets is of course, a particularly poor borough. However as recent NDT reports show, in fact most authorities still 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, and doing this in ways which are properly responsive to the situation of black and ethnic minority groups.

* For children, for example, there is commonly a need for further efforts to provide individualised support, improved service coordination and to encourage integration into local communities.

* For young people and adults there are major tasks in widening opportunities for employment and offering alternative homes for the many people still living with their parents.

* In many places there is a significant need to improve the quality of existing community services.

* And across the country, it remains an urgent priority
  to complete resettlement of the 30,000 people (in
  England) still living in NHS institutions.

However, far from moving forward on these tasks, there is
currently a real danger that the modest successes we have
achieved in the 1980s will be used as the excuse to de-
prioritise the interests of people with learning difficulties
during the upheavals in public services flowing from the two
White Papers in 1989 and as a consequence of other policies
designed to control public expenditure.4

The challenge for the 1990s is therefore two-fold. We must
mobilise our collective energies to resist this threat and
continue to campaign for the rights of people with learning
difficulties to be supported as full members of society. We
must also use what we have learnt during the 1980s to inform
the large-scale strategies now required to make decent
opportunities and services widely available.

How this latter objective is to be achieved has been the
focus of the work we are currently undertaking at the King's
Fund College. With support from the Joseph Rowntree Memorial
Trust and the Mental Health Foundation, we have been trying
to provide direct assistance to local groups and agencies as
they have set about achieving strategic change. Over the
last three years we have worked with large-scale initiatives,
for example in Birmingham, Camden, Kent and Southwark, and
with regional strategies in the South West of England, Wales
and the Australian State of Victoria. We have also had the
opportunity to test ideas emerging from these initiatives
with local leaders from other parts of the country, and to
compare British experience with exemplary developments
elsewhere, particularly in North America. Increasingly all
this work has sought to take on board the changing situation
created by new government policies, particularly the <u>NHS and
Community Care Bill</u> and the <u>Caring For People</u> White Paper.

This work has provided us with the opportunity to identify
more clearly the necessary elements in concerted local
strategies for principled change. It suggests the changes
in national policies now required if these are to promote and
support effective local action. And it underlines the
importance of our personal contributions to building
community with people with learning difficulties, their
families and friends. The main lessons in each of these
areas are summarised in what follows.

<u>Building local strategies for principled change</u>

Reviewing this variety of local experience, we have concluded
that there are no short cuts to securing and sustaining
better lives for vulnerable people. Building more inclusive
communities is necessarily a lengthy, challenging,
frustrating but rewarding process which requires the very

best of our collective intelligence and commitment, while keeping us humble about the state of our art and the extent of our achievements.

Nevertheless it _is_ possible to draw from this wealth of experience a picture of the common elements which seem to characterise the most successful public sector initiatives (Figure 2).
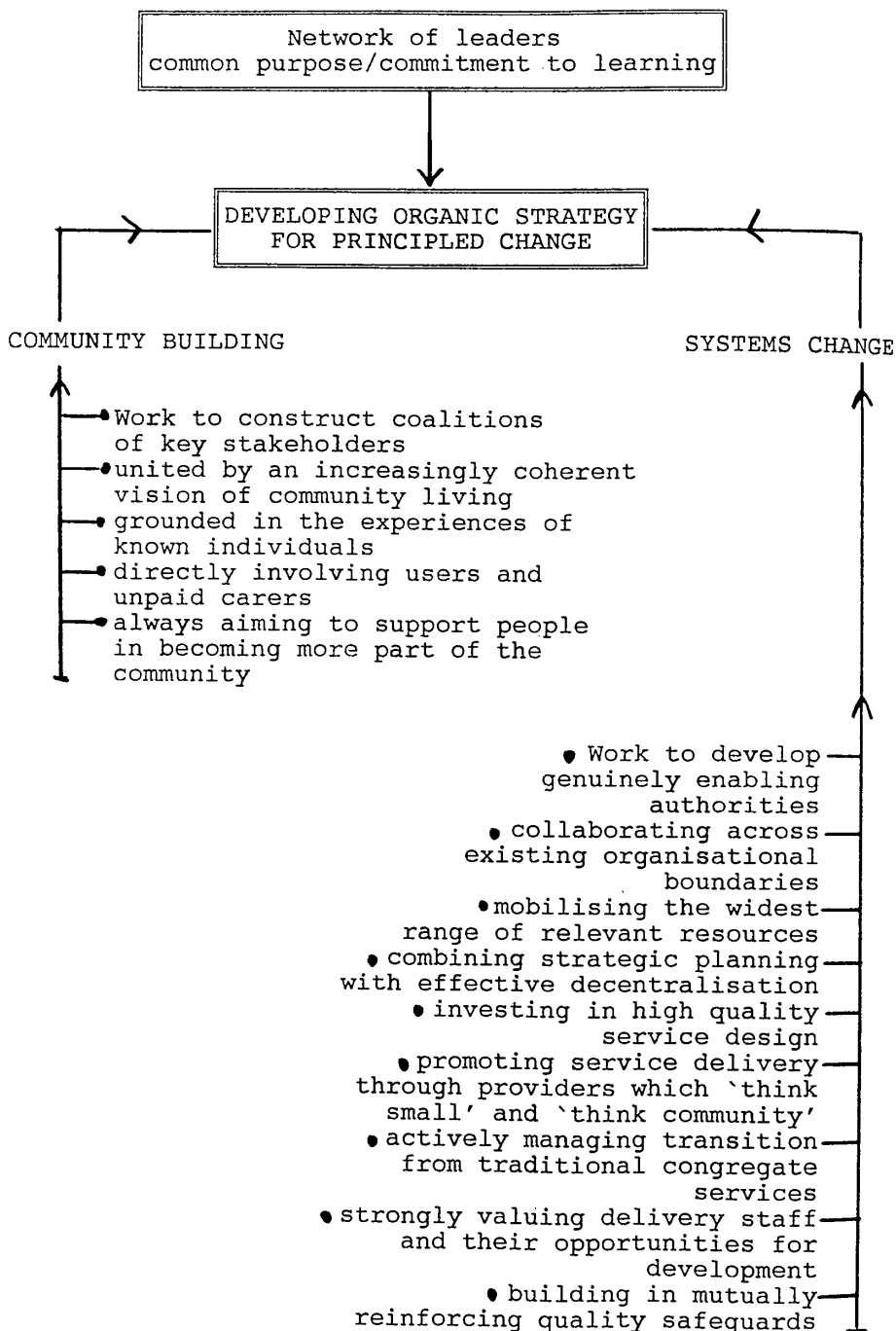
There are a lot of points here. We have seen that:

* Success is not just about signing up to the principles of `an ordinary life' : knowing where you are going is of course very helpful but there are far too many places where published plans are full of good intentions but these do not seem to be reflected in most clients' experiences.

* Success is also not in our view mainly a product of new systems like case management and purchase of service contracting required by the White Paper. Arrangements which focus service design on individuals and ensure diversity in service provision again may be very helpful, but there are plenty of places in North America which demonstrate all the Caring For People requirements and more, while still leaving people living in nursing homes or attending segregated day care.

* Success is not even initially about money. Of course money too is very useful and good services need to be paid for, but it is probably true to say that generating more adequate resources and using them appropriately is typically as much the consequence as it is the cause of effective local action.

Rather, if there is _one_ requirement which seems fundamental, it is the development of a network of leaders who share a common sense of purpose and a commitment to learning from both successes and disappointments as change proceeds. This requirement is straightforward in the sense that it reflects recent thinking about strategic management in other organisations,5 in part at least captured in well known textbooks like In Search Of Excellence.6 It is also subtle however in that 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, we have also been able to identify which pieces of the puzzle it seems most important to engage with in building effective local strategies. These fall into two inter-related sets, concerned respectively with community building and systems change.

Figure 2

BUILDING EFFECTIVE LOCAL STRATEGIES

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┌──────────────────────────────────────────┐
│             Network of leaders             │
│ common purpose/commitment to learning      │
└──────────────────────────────────────────┘
                      │
                      ▼
        ┌──────────────────────────────────┐
  ──→   │ DEVELOPING ORGANIC STRATEGY       │   ←──
        │    FOR PRINCIPLED CHANGE           │
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COMMUNITY BUILDING   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 which `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

We have learnt that achieving principled change is
essentially a political process. People with leadership
opportunities both inside and outside the public agencies,
have had to work - sometimes over several years - to
construct coalitions among the key stakeholders in order to
exercise real influence on local decision-making. This work
has taken different forms:

*   In Southwark, for example, one product of these
    efforts was the formal consortium of funding and
    providing agencies which has shaped the local
    services to replace Darenth Park Hospital.[7]

*   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 focused 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.[8]

We have learnt that these coalitions need to organise around,
and actively promote an increasingly coherent vision of what
life as part of the community should mean for people with
learning difficulties having regard both to changes during
the life-cycle and different cultural expectations. In all
the places we have been working - and most notably in Wales -
we have seen 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.

We have learnt - as the latest Open University[9] materials in
this field describe so well - that service development
should begin - and end - with the needs and wishes of
individuals. Expressed more technically, we need imaginative
approaches to personal futures planning in which people with
learning difficulties, 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
Wakefield and Winchester case management projects, it
provides an important vehicle for helping people gain more
control over their lives and build bridges to the wider
community. If we can get this working right, it also offers
a powerful stimulus for gradually remodelling the whole
pattern of inappropriate existing provision.

It is axiomatic of course that the views of service users
must be at the centre of these individual plans but we
have also learnt, not least from the growing voice of

self-advocates, how important it is to directly involve
people in shaping these wider changes. We have seen, for
example, in Grimsby and Birmingham, how public agencies are
beginning to open up their bureaucracies to the views of
users and unpaid carers through a variety of participative
arrangements.

And belatedly perhaps we are learning to think carefully
about the meaning of community to people with learning
difficulties as we recognise the crucial importance of ties
and connections in all our lives. As <u>Developing Friendships</u>
describes[10], we have begun to appreciate the different ways
in which support might be offered so as to strengthen
community integration, and therefore to think about how best
to design services which enable people to live fuller lives
without becoming wholly incorporated into the world of paid
providers.

With these five 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. We have seen some elements of the
new approaches which seem to be necessary in places as
different as Camden and Kent, and in trying to understand how
best to make use of the recent White Papers, we have also
drawn lessons from demonstrations elsewhere, for example in
Wisconsin and Western Massachusetts.[11]

In most places we still have a long way to go, but we have
begun to see that the idea of public agencies acting as
enabling authorities can be a positive one, providing we
understand enabling in its true sense - of using their
democratic authority and organisational power to work for
local communities which include people with learning
difficulties as full members.[12] Given the structure of our
public services, this continues to imply the need for
collaborative efforts across the 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 a lot more people with disabilities
get proper jobs. It also implies the need for these
authorities to mobilise the widest range of relevant
resources, not just the cash tied up in specialist services
but also contributions for example, from housing, leisure,
education and employment creation, in order to widen the
opportunities and support which are made available.

We have learnt that 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 the corporate vision, with the decentralisation
necessary to ensure that services are designed and money
spent close to the users. In the context of <u>Caring For
People</u> we have seen from North American experience that the
key requirement here is skillful management of the triangular

relationship between strategic planning, the purchase and provision of services, and the arrangements for tailoring opportunities to meet individual needs (represented in Figure 3).

In making these systems work, we have learnt, for example, from the best projects providing ordinary housing options for people with severe disabilities in Bristol, Cardiff and Winchester, and also from the more recent supported employment projects in places like Hammersmith and Sheffield, that the development of good quality services is both technically and managerially demanding. The public authorities need therefore to make a significant investment in staff with the necessary skills and commitment to help establish the new services required to offer people, particularly those with more complex needs, genuine choices among desirable alternatives.

We have learnt, for example from the experience of the best voluntary organisations like CSMH in Camden and Barnardo's 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 of us take for granted.

Given the challenges I described at the outset, we have also learnt that this emphasis on the development of community-based services still needs to be complemented by a major investment in properly managing the transition from out-dated institutional provision, and we know a lot about what this involves, for example from the detailed study of the Darenth Park closure and from other initiatives like the Kirklees relocation study.[13]
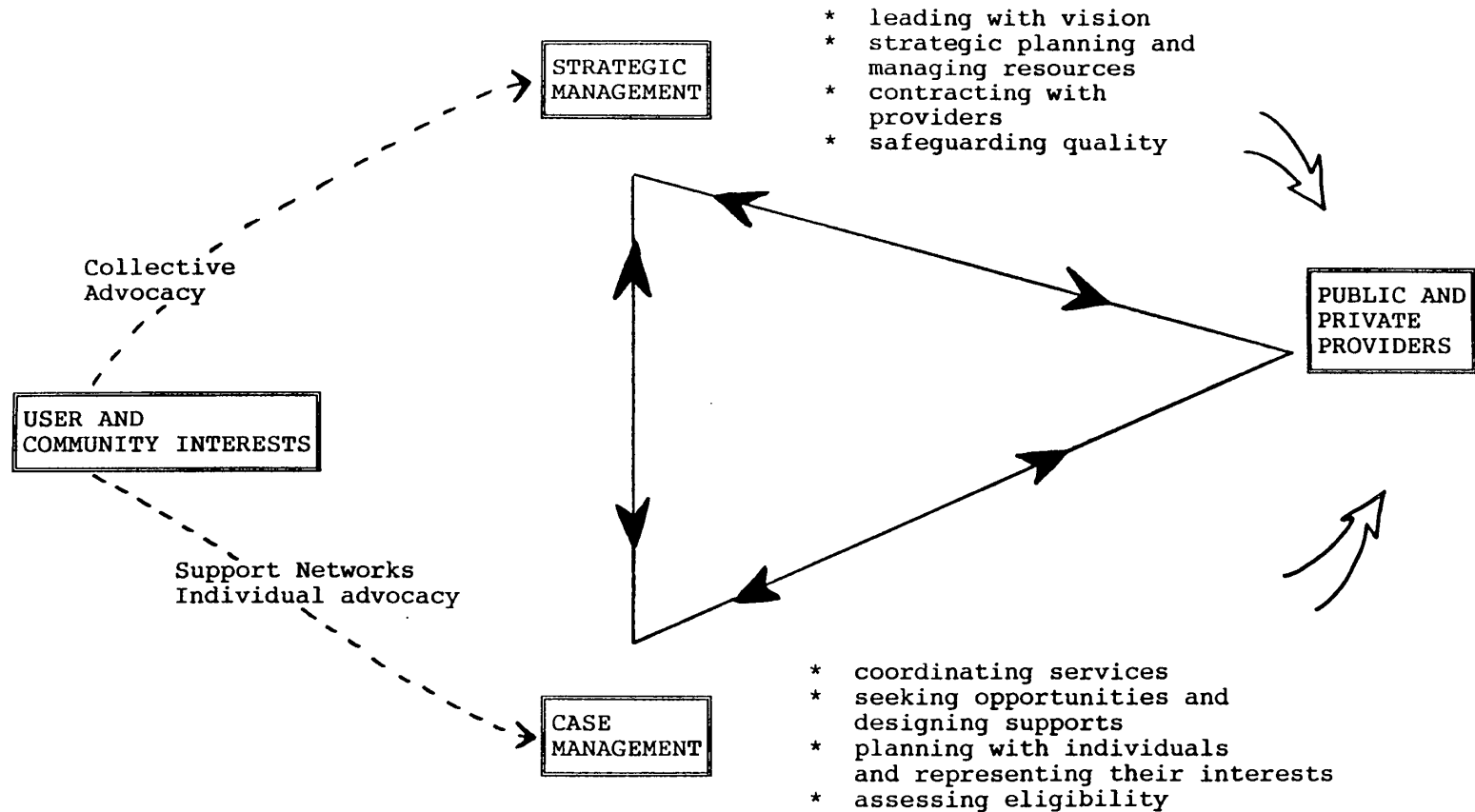
We have learnt that we are likely to be more successful in all these things where employing authorities demonstrate that they value the contribution of their staff and take seriously their needs for relevant training opportunities.[14]

And last but not least on this list, we have learnt that the quality of local services needs to be carefully safeguarded, not just by managerial action and the development of quality action groups like those proposed by the IDC and being developed at the Norah Fry Research Centre[15], but also by

strengthening independent inspection procedures and opening up services more to the views of users and citizen advocates.[16]

We will not, of course, get all these things right all of the time. But to change the metaphor with which I started, if we are able locally to tie these fourteen strands of activity together we should be able to make a strong rope to pull ourselves into the 1990s.

FIGURE 3 - <u>KEY FUNCTIONS OF THE ENABLING PUBLIC AUTHORITY</u>

STRATEGIC
MANAGEMENT

*   leading with vision
*   strategic planning and
    managing resources
*   contracting with
    providers
*   safeguarding quality

Collective
Advocacy

USER AND
COMMUNITY INTERESTS

PUBLIC AND
PRIVATE
PROVIDERS

Support Networks
Individual advocacy

CASE
MANAGEMENT

*   coordinating services
*   seeking opportunities and
    designing supports
*   planning with individuals
    and representing their interests
*   assessing eligibility

Implications for national policy

What implications can we draw from this analysis for the
national policy framework required to support effective local
action? If we are to take the Caring For People White Paper
as a starting point, we should also recognise that its
general proposals have major weaknesses as these relate to
services for people with learning difficulties. The very
brief section devoted specifically to 'priorities for people
with a mental handicap' is notable chiefly for its failure to
identify priorities beyond the wish to promote further
progress within available resources. This is particularly
disappointing in contrast with the situation in Wales where
the Welsh Office is aiming to use the White Paper to build on
the impetus already offered by the All Wales Strategy.[17]
Indeed as the IDC argues, current policies outside Wales may
actually set back the modest progress of recent years unless
Government acts soon to give fresh momentum to a positive
programme of reform.[18]

Fortunately Ministers seem now to have heard this message and
a new policy statement, nearly 20 years on from the 'Better
Services' White Paper, is promised for the autumn. Drawing
on the experience of major policy initiatives elsewhere, for
example, the 1986 legislation and ten year strategy adopted
in the Australian State of Victoria, the recent federal
initiative in Canada, and the seven years of progress through
the All Wales Strategy, we can map out what this statement
will need to cover if national policy is to reinforce
principled local change.

The central lesson from this experience is that Government
cannot be neutral to the fate of people with learning
difficulties and their families. Ministers can use their
democratic authority and the power and influence of
Government to set objectives, provide incentives and support
developments which promote desirable outcomes for people with
learning difficulties. Or they can fail to do so.

Our analysis suggests twelve key elements in a positive
national policy framework on which the autumn statement might
build (Figure 4).

If Ministers are to give fresh momentum and direction to
these services, it will be crucial that they restate strongly
the Government's vision of the opportunities and support
which should be available to enable people with learning
difficulties to enjoy a full life within the community
(building here on the principles identified in the All Wales
Strategy).[19] Among other things, this statement of purpose
will be essential both to inform and assess the community
care plans now being produced by local authorities.

A positive vision of this kind will of course require a
policy framework which goes much wider than the specific
responsibilities for health and social services which
preoccupy the Department of Health. There is a clear need

Figure 4

TWELVE ELEMENTS IN A POSITIVE NATIONAL POLICY FRAMEWORK

i.   A 1990 policy statement on enabling people to enjoy a full life within the community

ii.   Interdepartmental collaboration to promote conditions supporting this objective

iii.   Action to promote user participation in the design of opportunities and services to meet individual needs

iv.   Full implementation of the 1986 Disabled Persons Act

v.   Support to developing independent advocacy

vi.   Clear identification of the tasks required of local authorities, the NHS and other agencies

vii.   Planning and review procedures to integrate these contributions

viii.   Identification and protection of the necessary public sector resources

ix.   Central incentives, advice and support for effective implementation, particularly to:

- integrate children and young people in local communities
- provide adults with homes of their own
- extend opportunities for real jobs
- promote access to generic services

x.   Fresh incentives to complete resettlement of the 30,000 people living in NHS institutions

xi.   Major investment in developing appropriately skilled staff for new services

xii.   Better arrangements for safeguarding quality

for stronger inter-departmental collaboration (ie. between the Departments of Health, Education, Environment, Employment and Social Security) to promote the conditions for community living.

Ministers will need to emphasise the importance of meeting the individual needs of people through individual service plans and case management; strengthen their rights in these arrangements by full implementation of the 1986 <u>Disabled Persons Act</u>; and provide central support for the widespread development of robust independent advocacy services.[20]

Ministers will need to identify clearly the distinctive strategic challenges confronting services for people with learning difficulties in implementing these intentions, and specify the key tasks which local authorities, the NHS and other agencies therefore need to tackle. They will need to ensure that the new national planning and review procedures work to integrate the contributions of local authorities and the NHS and to monitor progress. They will need to take steps both to identify and protect the public sector resources required to carry out these tasks effectively.

More specifically, Ministers will need to provide the incentives, advice and support required to promote widespread development of local opportunities and services consistent with the national vision, focussing particularly on:

- ensuring that children and families receive the interdisciplinary and individualised assessment and support provided by the 1981 <u>Education Act</u> and the <u>Children Bill</u> so as to encourage their community integration;

- providing adults with the housing and support they require to move when they wish to homes of their own;

- encouraging major change in existing day services towards a wider range of opportunities, centred on supported employment (and tackling therefore the Social Security disincentives to people getting real jobs);

- promoting better access for people to 'generic' services (eg. in the fields of health care, education and leisure).

Ministers will also need to make clear the Government's commitment to completing resettlement of the 30,000 people (in England) and redeployment of staff from the NHS institutions, showing how the bridging costs of this transition are to be funded in the new context created by the <u>National Health Service and Community Care Bill</u>.

Ministers will need to promote the workforce planning and training arrangements required to provide appropriately skilled (and valued) staff for the new patterns of provision in the 1990s and beyond.

Enabling people with learning difficulties to make and maintain friends London, Policy Studies Institute, 1989. For an excellent Canadian example, see also *The Power Of Positive Linking* Downsview, Ontario, G. Allan Roeher Institute, 1989.

11. For a fuller discussion, see Thomas, D. and Towell, D. 'Common Goals Across Oceans' *Health Services Journal* 4 January, 1990. A very useful analysis of recent experience in the United States is provided by Taylor, S. J., Bilken, D. and Knoll, J. (eds) *Community Integration for People with Severe Disabilities* London, Teachers College Press, 1987.

12. For a particularly helpful conceptualisation of the 'enabling authority' in these terms, see Stewart, J. and Stoker, G. *From local administration to community government* London, Fabian Society, 1988.

13. See respectively Korman, N. and Glennerster, H. *Hospital Closure* Milton Keynes, Open University Press, 1990. and Booth, T., Simons, K., and Booth, W. *Outward Bound : Relocation and Community Care for People with Learning Difficulties* Milton Keynes, Open University Press, 1990.

14. See for example, the South East Thames Region's experience described by Mansell, J. 'Training For Service Development' in Towell, D. (ed) 1988. *op cit*

15. Independent Development Council For People With Mental Handicap *Pursuing Quality* London, IDC, 1986. The Norah Fry project is publishing a *Quality Action Resource Pack* in 1991.

16. The need for a mutually reinforcing set of quality safe-guards is well described in the All Wales Mental Handicap Strategy Advisory Panel's paper on *Proposals For The Independent Review Of Services For People With Mental Handicap In Wales* Cardiff, The Welsh Office, 1989.

17. See respectively, Cm 849 *Caring For People : Community Care In The Next Decade And Beyond* London, HMSO and *Caring For People : The Proposals For Wales* Cardiff, The Welsh Office, 1989.

18. *Cinderellas Again?* IDC, 1990. *op cit*.

19. Again, there are helpful models elsewhere of what this might involve. See, for example the visionary but practical manifesto of the Canadian Association For Community Living *Community Living 2000* Downsview, Ontario, CACL, 1987.

20. A useful model for all these proposals is the Australian State of Victoria's <u>Intellectual Disability Services Act 1986</u>. For further discussion see Towell, D. `Victorian Community Care' <u>Social Services Insight</u> 30 August 1988 and Burton, M. <u>Australian Intellectual Disability Services - Experiments in Social Change</u> London, King's Fund College Building Community Strategies Working Paper, 1989.

King's Fund College
2 Palace Court
London W2 4HS
Tel: 071-727 0581

2 020000 048572 0