

**Joint Strategy Group**

# **A Strategy for the 1990s**

Services for People with Learning Disabilities  
in Greater Manchester and Lancashire

## Preface

As Chair of the Joint Strategy Group on Services for People with Learning Disabilities in Greater Manchester and Lancashire, it is my pleasure to introduce this document to you.

Much has been achieved in recent years in the north west, in providing better services for people with learning disabilities. The document *A Model District Service* was the catalyst for many changes. But the world moves on, and we must review and restate the strategy for the remainder of this century and beyond. That is the purpose of this document. We are grateful to all who have helped to produce it, and to comment on the draft.

We finalise this document at a time when the North Western Regional Health Authority, under whose auspices so much has been achieved, is about to merge into a new and much larger Region.

It is the hope and intention of the Joint Strategy Group that all the work of the last 15 years should continue to be developed in the ways envisaged in this document, despite the many constraints upon us all. We invite you all to join in this endeavour to secure an even better future for people with learning disabilities.

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## **Acknowledgement**

Grateful acknowledgement is made to John O'Brien who has helped guide service developments for people with learning disabilities in the north west for over a decade. This strategy emerged from a day of discussion by 40 people from around the north west in November 1992 facilitated by John.

## Summary of Main Recommendations

### Main Themes

#### Basic values

1. We need to reaffirm the basic values which hold good regardless of the structures services adopt and whatever the pressures for organisational change might be.

#### Opening up community resources

2. Disability is a community issue, not just a service responsibility. We should seek out and develop natural supports. To do this we should allocate resources from services to facilitate the shift from services to community.

#### Empowering those who rely on services and their carers

3. Service workers, managers, policy makers and planners need to listen to the voices of service users, families and those closest to them. They need to search for ways to involve those they serve and carers more actively in decision making, both at the individual level and more broadly in wider service development. They need to empower service users and parents. They need to move from domination to partnership.

#### Promoting quality

4. We should be constantly seeking quality both in the lives of people with disabilities as well as in the services and help on which they depend.

#### Region-wide co-ordination

5. The need for steering change region-wide remains. The alliances and networks that have been built up need to be nurtured.

### Services

#### Purchasing

6. Purchasers need to be clear about the underlying values and how services can be designed which derive from those values.
7. Purchasers operating in the same locality, in health, social services and education need to co-operate so as to develop a common understanding and a coherent approach to the needs of those they serve. Joint commissioning would be the most effective way to do this.
8. Purchasers need to have strong links with people they serve and carers to understand the relevance of the services they are commissioning to people's needs. These links should be based on personal contact.
9. Purchasing contracts should specify quality with relevant outcome measures and feedback mechanisms which enable quality to be enhanced.

#### Services to children

10. Parents need to learn of their child's disability in a way that helps them to adapt to the news as effectively as possible.
11. Parents need guidance on opportunities for including children in mainstream education and other pre-school provision from the time they learn of their child's disability.
12. Health and Social Services should liaise with Education much more closely at all stages and levels.

13. Parents and teachers need guidance on building circles of friends around children.

### **Services to adults**

14. The key tasks in services to adults are:

- a) to continue the resettlement of people from hospitals and hostels
- b) to make available alternatives to the family home, at an appropriate chronological age, for those who never left for hospital or hostel
- c) to develop integrative day activities including employment and education so that people do not have to spend their days congregated in day centres
- d) to continue to develop more effective means of meeting the needs of people whose behaviour challenges services to support them in ordinary living, and those who offend against the law
- e) to address the needs of people with profound and multiple disabilities and their families more effectively.

15. We should continue to encourage support options for a place to live beyond the staffed group home and adult placement models but which are still domestic scale and integrated.

16. Local authorities should plan to shift away from services based on attendance at the traditional adult training centre, towards an approach to day services based on individual assessment and programmes, in which skill learning and vocational preparation are prominent. The aim should be to move towards a personally planned programme of day activities - social, educational, vocational and leisure - which make use of ordinary community facilities wherever practicable.

17. The conversion of day centres to dispersed services needs to be planned systematically.

18. In planning for transition from school detailed information packs on all options available together with opportunities to meet and discuss with representatives of all the agencies offering services would enable students and their parents to make informed choices about next steps.

19. Supported employment should be given high priority for development.

### **Education**

20. It should be seen as every child's entitlement to be included in their local mainstream school whatever their needs.

21. We have to see the school as a community and aim to celebrate differences between children so that each child, no matter what their labels, can feel they belong.

22. Each local education authority should have a clear statement of its policy on integration, developed in consultation with parents and professionals, as part of its overall policy on special education.

23. Parents of children with special educational needs should have the same entitlement as parents of non-disabled children to state their preference as to which school they wish their child to attend. This entitlement should be stated in local education authority policy and all schools encouraged to adopt it in their policies.

24. Every child with special needs under five should be entitled to experience group learning with other children of the same age who do not have special needs.

25. Mainstream schools should be encouraged to adopt policies which stress the importance of including all children no matter what their disability.
  26. Each mainstream school should be seen to take responsibility for serving all children in its area. Every child should have the opportunity to be enrolled at the local neighbourhood school they would expect to attend if they were not disabled, even if they attend elsewhere.
  27. As every child has entitlement to the national curriculum every school should be flexible enough to accommodate a wide range of difficulties. All schools should be preparing students for adult life whether they have special educational needs or not.
  28. Children should be included in all aspects of school life as far as practicable.
  29. Every learner should have the opportunity to move on from school to college at 16 years. At college they should use the ordinary resources available to other students with the support that they need: student services, mainstream classes, lecturers and tutors. Special needs should not be a subject in which students are enrolled, although there will be a need for learning support co-ordinators or tutors to guide the development of inclusion in colleges.
  30. Each college should have a statement of policy affirming inclusion.
  31. At each transition point there should be information on all the options available given to the family so that they are able to make informed choices.
- Health gain**
32. Health purchasers and providers will need to review what is required to meet the health care needs of people with learning disabilities.
  33. Overall health gain goals are:
    - a) to reduce avoidable premature deaths
    - b) to reduce preventable morbidity
    - c) to achieve measurable improvements in health status
    - d) to support developments that maintain the health of carers.
  34. The health service should help make social integration a reality.
  35. The health service should promote and maintain the health of people with a learning disability.
  36. People with a learning disability have a right to co-ordinated health care

**Forensic services**

39. People with learning disabilities who have offended against the law should be cared for:

- a) with regard to the quality of care and proper attention to the needs of individuals
- b) as far as possible, in the community, rather than in institutional settings

c) under conditions of no greater security than is justified by the degree of danger they present to themselves or to others

d) in such a way as to maximise rehabilitation and their chances of sustaining an independent life

e) as near as possible to their own homes or families if they have them.

## Introduction

Bringing a strategy up to date has to be done every few years to accommodate changes brought about by the efforts of previous years as well as changes in the wider environment.

In the North Western Region over the last ten years, there has been an increasingly strong tradition of developing and reviewing policy through region-wide inter-agency groups. This began in the early 1980's with the Regional Advisory Group for Learning Disability Services (formerly Mental Handicap Advisory Group). The Regional Training and Development Teams reflected this approach, which was further strengthened by the formation of a Strategy Steering Group in 1989, to drive forward the resettlement strategy outlined in *Shared Proposals for Shared Problems*.<sup>1</sup>

In April 1992, The Joint Strategy Group was formed, to embrace the SSG's resettlement task and the wider remit of all learning disability services in the North West. This coincided with the formation of a single North West Training and Development Team, with a workload defined by The Joint Strategy Group. It was recognised that a work programme needs to be set in the context of a clearly defined vision and a set of objectives for region-wide work as a whole. This in turn suggested the need for a stock take of the progress to date, and a shared approach to the future task. Accordingly a full day workshop was held in Whitefield in November 1992, attended by 40 people representing a wide range of interests. This paper builds on that day's debate and is offered for wider discussion.

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<sup>1</sup> NW Review Working Group 1989 *Shared Proposals for Shared Problems*

*A Model District Service*<sup>2</sup>, produced in 1982, focused on the need to develop community services. This led to a major resettlement programme in the NW from the long stay hospitals to dispersed housing throughout the region. Over 1300 people have now moved from hospital to community living in the past 10 years. This has been a driving force behind many of the changes of the past decade. In addition, local authorities have developed a substantial programme of hostel closures. Over 600 people have moved to ordinary accommodation from hostels since 1985 and 24 hostels have closed. Altogether, close on 2000 people are now living in domestic scale ordinary housing who were previously in institutions.<sup>3</sup>

Day services are changing too. Many people across the region are attending further and adult education instead of, or in addition to, adult training centres. Over 400 people with a wide range of learning disabilities are supported through employment schemes. Schools are beginning to respond too by including children in mainstream provision, even some with profound and multiple disabilities.

In 1988 a review took place resulting in *Shared Proposals for Shared Problems* which reaffirmed the strategy of developing community services and running down institutional provision.

Currently major upheavals in services are taking place resulting from Government policy changes<sup>4</sup>. The purchaser/provider restructuring is affecting Health, Social

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<sup>2</sup> NWRHA 1983 *A Model District Service* NWRHA: Manchester.

<sup>3</sup> NWTDT 1992 *Patterns of Change* NWTDT

<sup>4</sup> See: DoH 1990 *NHS and Community Care Act* and Policy Guidelines accompanying *Caring for People* and *Working for Patients*

Services and Education and of course voluntary agencies.

This is, therefore, a time of turbulence in services: unprecedented increases in complexity, speed of change and uncertainty. It is essential that we check our direction and make sure our map is up to date.

A companion strategy on training to implement this strategy is available<sup>5</sup>

## Basic Values

Values are what people think are good and worthwhile and are willing to work for. They attract energy, enthusiasm and commitment. Values shape service design whether we acknowledge them or not. Any service reflects the values of those responsible for them. Explicit values enable us to handle the practical dilemmas that arise in services in a coherent way.

We need to reaffirm the basic values which hold good regardless of the structures services adopt and whatever the pressures for organisational decline might be. There is a tendency for systems to degrade over time towards disorganisation. Organisations tend to drift as aims and objectives get displaced and vision is replaced by inertia. These are inevitable tendencies in all organisations.

A set of negative pressures is influencing services. The emphasis on markets and competition is in danger of leading to a decrease in co-operation between providers. The financial pressures and uncertainty accompanying the new patterns of service are leading to disengagement and a climate of cynicism among workers, families and

people who need supports to lead an ordinary life. As people become dispersed and absorbed into the daily life of the community, they are in danger of becoming increasingly invisible to services and may lose out. We need to resist these pressures by keeping the basic values clear.

The vision, as stated in *A Model District Service*, which has guided service development in the NW for the past decade remains the same (see appendices 1 and 2):

- no one is excluded from taking their place in the life of their community, with the supports they need, at each stage of life including pre-school, school, college, employment, a place to live, leisure and worship. The aim is to include everyone, even those with profound or multiple disabilities or whose behaviour challenges services.
- each person is treated as an individual with supports appropriate to their needs
- users of services and their families are able to influence the services available and received so that service workers move from domination to partnership
- people should not have to go outside their communities to receive the majority of services which should be local and comprehensive

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<sup>5</sup> NWTDT 1993 *Towards a Region-Wide Training Strategy for the 1990s*

- service workers should recognise that the service is there for the people being served. Values of power, prestige and privilege for workers in services should

be replaced by values of healing, empowerment and restoration for those being served.

<b>Valued Experiences</b> (for people with learning difficulties)	<b>Community Challenge</b> (the aims we are working to achieve)	<b>Service Accomplishments</b> (what the service should aim to achieve)
Sharing ordinary places	Include all people and activities	Community presence
Making choices	Protect integrity by creatively resolving conflicts	Protecting rights and promoting choice
Developing abilities and sharing personal gifts	Develop all available resources wisely	Recognising interests and gifts; improving competence
Being respected and having a valued social role	Offer valued roles to everyone by confronting limiting beliefs and their historical consequences	Promoting valued roles
Growing in relationships	Promote interdependence among people	Community participation

**Table  
Showing Accomplishments**

These basic values are the same values that under-pin Care in the Community<sup>6</sup>.

A formulation which has guided service developments throughout the north west over the past decade inter-relates three different perspectives: the experiences of the person with learning disabilities, the accomplishments of the services, and the

aims we are working to achieve<sup>7</sup> (see table above).

In alliance with others, services need to make an explicit commitment to learning better how to identify needs and how to respond to them. This requires an approach which acknowledges our ignorance, error and fallibility and is open to identifying problems and seeking solutions. As we

<sup>6</sup> See footnote 4.

<sup>7</sup> O'Brien, J and Lyle O'Brien, C 1990 *Framework for Accomplishment* Responsive Systems Associates: Lithonia, Georgia.

engage with problems we need to acknowledge that co-operation and consensus are needed.

## Opening Up Community Resources

As people take their rightful place in the life of their communities it becomes apparent that there needs to be a balance between what ordinary people and paid services can do in providing support.

Most of the attention of service administration is focused on 'how to get and keep staff, how to process people and papers, how to manage relationships with the larger service system to maintain legitimacy and maximise resources. In theory the organisation takes people in, processes them to produce changes, and discharges them cured or retains them. The basic strategic tasks change this self absorbed picture. Effective services refocus the people and money available to them on opening more community opportunities to people who might otherwise be excluded'<sup>8</sup>.

Service workers don't have to feel that the responsibility is purely on services to provide the help that is required to ensure that people's needs are met. Friends, neighbours, family members and other unpaid people have a part to play. Services should encourage and enable them to be involved and not stand in their way.

Seeing people with disabilities in the context of community and shifting the balance from service to community supports will increase the resources available. This should not be

seen as a way of saving money for hard pressed services or a way of providing service on the cheap.

Disability is a community issue, not just a service responsibility. We should seek out and develop natural supports. To do this we should allocate resources from services to facilitate the shift from services to community. For example, developing support circles around individuals will benefit from paid co-ordinators who might be parents who have gained the experience of setting them up for their own sons and daughters.

If people who require supports to lead an ordinary life are to widen their range of contacts outside the 'world of handicap' (family, paid services and other users) many will need assistance. We need to learn how to invite people into their lives.

There has to be a partnership between community and organised services, a wider coalition, building alliances across traditional boundaries. Services have to be prepared to pass their mission to the community. The community has a lot to gain from this shift. As we learn how to build community and a sense of belonging for vulnerable citizens we strengthen possibilities for us all. This will help to develop communities that are more competent in responding to the needs of **all** their members.

Some implications for development:

- Service workers need to listen, understand and respond to the people they serve.
- Where unpaid citizens can provide support, services should encourage them.

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<sup>8</sup> O'Brien, J and Lyle O'Brien, C 1990 *Framework for Accomplishment* Responsive Systems Associates: Lithonia, Georgia.

- Services should not try to take over people's lives but shift the balance to natural supports until the minimum necessary paid services required are involved.
- Parents should be helped to draw on natural supports.
- Services need to be flexible and adaptable to work alongside natural supports.
- The benefits of employing local staff who already have their own networks should be recognised.
- Service workers and family members need to understand how relationships develop and search for opportunities to build community around people who need supports.
- Service workers should shift their role from doing things for the person they serve so that they can *enable* contacts to develop. This means being ready to stand back as relationships begin to develop. They need to learn how to invite unpaid people into the lives of people who use services.
- The gifts and contributions of people with learning disabilities to communities need to be recognised.

Continuing attention will be needed to safeguard people with learning disabilities from abuse of all kinds, neglect and exploitation.<sup>9</sup>

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<sup>9</sup> NWTDT, 1993, *Abuse Awareness & Actions: Guidelines for recognising and responding to abuse, exploitation and neglect of adults with severe learning disabilities.*

None of this should be interpreted as a justification for leaving people with insufficient support.

## Empowering Those who Rely on Services and their Carers

Service workers, managers, policy makers and planners need to listen to the voices of service users, families and those closest to them. They need to search for ways to involve those they serve and carers more actively in decision making, both at the individual level and more broadly in wider service development. They need to empower service users and parents. They need to recognise that some users and carers don't trust services and acknowledge the legitimacy of their concerns. They need to move from domination to partnership.

Of course there won't always be agreement among user, carers and services (purchasers and providers). When there is disagreement negotiation will be needed to arrive at a decision, with meeting the needs of the user being the priority consideration.

Special efforts are needed to enable users and carers from ethnic minorities to influence service provision.

## Promoting Quality

Quality of life is defined in terms of valued experiences as listed in the table on accomplishments (page 3). Quality of service is defined in terms of fitness for purpose. Is the service appropriate and effective in meeting the needs of those served?

It is not enough to resettle people and place them in mainstream settings. They can be

isolated, neglected, abused and exploited in the community as much as they ever were in institutions. We should be constantly seeking quality both in the lives of people with disabilities as well as in the services and help on which they depend.

Promoting quality can be done through:

- Joint Strategy Group, as the guardian of the strategy, developing a culture which supports quality even though its membership changes
- Joint Strategy Group using its influence for quality to be included in contracts. Purchasers may need guidance in developing contracts that include attention to outcomes in the daily lives of those who rely on services.
- local authorities adopting corporate policies which embody social role valorisation. Most local authorities are already committed to reducing discrimination through action on equal opportunities. In conjunction with the Chief Executive's Department, each department would consider how their practices and procedures can be developed so that the principle is implemented throughout the authority. This would include: education, social services, transport, leisure, housing, personnel, works, finance, competitive tendering, etc.
- disseminating good practice and news of innovative and effective ways of meeting needs as we learn from experience e.g., in newsletters, videos, conferences
- supporting, with funding, innovative efforts from which we can learn. This should be seen as investing in developing the next steps.
- giving recognition to quality developments which are often fragile and in danger of being marginalised
- providing guidance on ways of involving community
- service agencies must ensure that service quality and quality of life are monitored and reviewed for each person served. Both internal and external reviews are needed. Training in how to review quality is needed.
- integrating audits of services in a multi-agency, multi-disciplinary process which reflects team working
- quality of services depends on flexibility in the use of resources and the imagination of care managers in service design.
- each person associated with services needs to recognise their responsibility in pursuing quality.

## Region-Wide Co-ordination

The benefits of co-operation across many boundaries (professional, agencies, geographical etc.) during the past decade are widely acknowledged. We have learned from each other. We have pooled resources. We have energised each other.

From the early 1980s under the auspices of the Regional Health Authority and the Mental Handicap Advisory Group (now the Advisory Group on Learning Disability Services) efforts were made to ensure that advice was co-ordinated across a wide range of agencies. More recently the Strategy Steering Group which later became the Joint Strategy Group took on a co-ordinating role, initially with the hospital resettlement

programme and in 1992 with the broader task of developing local and comprehensive services.

It is recognised that in future the Regional Health Authority role may decline. As it does the need for steering change region-wide remains. The alliances and networks that have been built up need to be nurtured. As people who use services and parents strengthen their voices they need to play more active roles in the steering process.

One of the roles of leadership at region-wide level is to inform central government of the need for, and growth in, community involvement and how this can be fostered. For example demonstrating the numbers of:

- people in ordinary housing
- people in employment
- adults still living with their families.

## Purchasing Services

In the new landscape of the 1990s purchasers of services play a key role as they determine what services are to be commissioned<sup>10</sup>. If they are to be aligned with the basic principles they need to be clear about the underlying values and how services can be designed which derive from those values.

Purchasers operating in the same locality, in health, social services and education need to co-operate so as to develop a common understanding and a coherent approach to the needs of those they serve. Joint commissioning would be the most effective way to do this. There is a major difference

between health purchasing which is concerned with aggregated needs and social services which is concerned with individual need. Services affecting one aspect of a person's life will have major influences on services needed in another aspect. These effects should be acknowledged and understood.

Purchasers need to have strong links with people they serve and carers to understand the relevance of the services they are commissioning to people's needs. These links should be based on personal contact. The needs of the people served should be brought to the attention of purchasers regularly and vigorously.

The key activity of purchasers is assessment to determine unmet needs and how best they can be met. This represents a shift away from assessment for service to the more primary task of assessment of need and identifying what supports are required. Only then can appropriate services be designed.

Purchasers need to be aware of the price-quality dilemma. Where paid service is required, paying less may mean unacceptably poor quality service although paying more does not necessarily guarantee better quality service. Contracts should specify quality with relevant outcome measures and feedback mechanisms which enable quality to be enhanced.

The situation of people who are now served outside their own communities in out of area placements should be reviewed. Resources used for such placements should generally be used to enable them to live in their own communities.

People with mild and moderate learning disabilities are in danger of falling through

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<sup>10</sup> See NWRHA 1993 *District Services Components for People with a Learning Disability: A Guide for DHA/FHSA Purchasers*.

the service net<sup>11</sup>. Some local authority providers are excluding them from their services. Purchasers will have the responsibility to ensure that adequate and appropriate services are recruited to meet their needs.

Purchasers will need to ensure that agencies train their staff to recognise and, where possible, respond to the special needs of people with autism.

Purchasers should:

- include in contracts mechanisms for monitoring and improving quality of services provided and quality of life experienced by those served
- talk with, and listen to, people who use services and their carers
- visit users of services and their carers
- help to drive quality
- recognise their capacity to co-ordinate supports and build a co-ordinated approach
- recognise the need for variety and flexibility in supports.

Service users, families and providers should keep inviting purchasers to see what life is like for people with disabilities.

## Services to Children

The emphasis during the 1980s on services to adults has changed what children with disabilities can expect as they grow up. In the past if a child didn't go into long stay hospital, schooling was for life in an adult training centre. The future is no longer so predictable. In adulthood the options for many are now much greater. Schools will have to prepare children for a wider range of possibilities, instead of putting them on a conveyor belt of segregation.

Changes needed include:

- helping parents to think about opportunities for including children in mainstream education and other pre-school provision from the time they learn of their child's disability
- articulating the vision in education and working towards schools and colleges which exclude no one
- Health and Social Services liaising with Education much more closely at all stages and levels
- helping parents and teachers to build circles of friends around children
- helping parents to learn of their child's disability in a way that helps them to adapt to the news as effectively as possible
- empowering parents so that they can work in partnership with others (including services) and not as subordinates
- extending in-home early intervention support (such as Portage).

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<sup>11</sup> See Burton, M 1990 *Caught in the Competence Trap*  
Regional Advisory Group for Learning Disability Services:  
Manchester.

## Services to Adults

The key tasks in services to adults are:

- to continue the resettlement of people from hospitals and hostels<sup>12</sup>
- to make available alternatives to the family home, at an appropriate chronological age, for those who never left for hospital or hostel
- to develop integrative day activities including employment and education so that people do not have to spend their days congregated in day centres
- to continue to develop more effective means of meeting the needs of people whose behaviour challenges services to support them in ordinary living and those who offend against the law
- to address the needs of people with profound and multiple disabilities and their families more effectively.

### A Place to Live

Resettlement from hospitals and hostels is now well established (see page 1). The programme of hospital run-down is on schedule to be completed by 2000. Rundown of hostels will continue as reprovision of supported living in dispersed ordinary housing is made available.

Staffed group homes and adult placements have been the main kinds of community provision for people being resettled but other possibilities have also been explored. We should continue to encourage support options for a place to live beyond the staffed

group home and adult placement models but which are still domestic scale and integrated. Valuable as these are they should be seen as but two of a variety of possibilities such as co-tenancies, share living, warden support for people dispersed in a block of flats or in a housing estate, and especially help tailored to the needs of individuals using natural supports possibly in combination with paid services.

If we really are committed to understanding the needs of each person and responding to those needs we must be more innovative. We must create organisational flexibility which can work with both natural supports as well as paid services to meet needs more appropriately and effectively.

There is continuing concern that services are not making adequate provision for people who never went in to hospital or hostel. This is a particular concern of the growing number of older parents who worry about what will happen when they are no longer able to support their son or daughter at home.

In-home support for parents is needed, especially where their son or daughter has challenging behaviour or profound and multiple disabilities.

### Day Activities for Adults

Now that the focus is on meeting the needs of users, it has become apparent that day centres cannot adequately meet their diverse individual needs.

Local authorities should plan to shift away from services based on attendance at the traditional adult training centre, towards an approach to day services based on individual assessment and programmes, in which skill learning and vocational preparation are prominent. The aim should be to move towards a personally planned programme of day activities - social, educational, vocational and leisure - which

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<sup>12</sup> Kagan, C. 1992 *Hostel Closure: Quality Contracts for Change* NWTDT

make use of ordinary community facilities wherever practicable.<sup>13</sup>

If individual needs are to be addressed we will have to seek out resources available to the rest of the community, always of course ensuring that support is provided appropriate to the person's needs. At the same time needs of family members also have to be addressed. The shift in day services can cause insecurity for some carers which is often greatly underestimated. Many will need reassurance about the benefits before they will accept them.

This shift to a dispersed service has to be tackled in two ways. Each individual should be given the opportunity to develop their personal future. At the same time, wider service planning is needed to make sure that a range of options is available.

### **Conversion of day centres**

The conversion of day centres to dispersed services needs to be planned systematically. This will require setting out the actions needed (transition arrangements for school leavers, development of further and adult education, supported employment, use of community centres) priorities and time scales. There will need to be discussions with those who attend, family members and staff so that they feel involved and can control the changes which will affect their lives.

Whatever the pattern of day activities, there should be continued entitlement to five day a week provision.

Priority focus could be given to those who would otherwise be about to enter day centres: school leavers.

### **Transition from school to adult services<sup>14</sup>**

Transition schemes (mentioned below under Education), developing in many parts of the NW, would provide a review of opportunities for each student at age 13+, including work experience during the year or two before leaving school, links with the local college of further education (see section on Education below), exploration of supported employment and training schemes. Detailed information packs on all options available together with opportunities to meet and discuss with representatives of all the agencies offering services would enable students and their parents to make informed choices about next steps.

### **Employment**

Supported employment schemes are now operating in almost all districts in Greater Manchester and Lancashire. Some are well established and well staffed so that every person with a learning disability has the opportunity of finding and trying a job of their choice. Some are very new with very few staff so that only a handful of people can be served.

Supported employment is such an important service that it should be given high priority for development. It should be seen as an investment which will enable resources to be transferred from being tied up in day centres. It should be seen as the aim towards which all people with learning disabilities should have the opportunity to move rather than an 'add on' to existing provision.

<sup>13</sup> Department of Health 1992 *Social Care for Adults with Learning Disabilities (Mental Handicap)* LAC(92)15

<sup>14</sup> See Department of Health 1991 *The Children Act Guidance and Regulations Volume 6 Children with Disabilities* HMSO: London.

The benefits trap continues to be a problem. Some parents are reluctant for their sons or daughters to try employment for fear of losing benefits and the difficulty of requalifying for benefit should the employment fail. In addition many families see benefit as part of the income of the household.

### **Community activities**

An alternative for day centre attenders who are unable or don't choose to explore supported employment or continuing education (such as people of retirement age) is to be based in local community centres. One day centre (in Oldham) is in the process of transferring people in groups of 12 with staff to community centres where a wide range of leisure and educational activities is available to everyone in the neighbourhood. This not only increases opportunities for integration but also for personal development.

In some places (such as inner urban areas) there may be few community activities to link with. Community regeneration and the skills of community development workers will be needed if people with learning disabilities are to participate actively in community activities.

## **Education**

'How can one feel a member of the human race if one is set apart from an early age?'<sup>15</sup>

### **Inclusion and Integration**

The term integration is understood in several different ways.

- *Locational integration* refers to having all learners on the same campus but with very little, if any, contact. The learners with special needs are taught in a separate classroom or even a separate building.
- *Social integration* is where learners with special educational needs eat, play and socialise with mainstream peers and may share organised out of classroom activities (assemblies, trips, swimming etc) but teaching is in separate classes.
- *Functional integration* means including all learners in every aspect of school life. Some learners may receive special support such as from a classroom assistant or some individual or group tuition, possibly outside the classroom.

The term inclusive education has come to be used widely in recent years to draw attention to the aim of actively welcoming children with special educational needs into the life of the mainstream schools they would expect to go to if they did not have a disability. Efforts are made to support the growth of relationships between those with special needs and those without. Simply being present is not enough. We have to see the school as a community and aim to celebrate differences between children so that each

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<sup>15</sup> Stephen Hawking, quoted in *Stephen Hawking: A Life In Science* by M. White & J. Gribbin, Penguin Books, 1992.

child, no matter what their labels, can feel they belong.

In discussions on integration there is much confusion over the use of the term and a wide range of views on what is best. In the move towards including learners with special educational needs in mainstream provision there is considerable anxiety. Some parents fear that special resources will be taken away. Some teachers in special schools fear that they may not have the skills to work as peripatetic advisers, supporting teachers and classroom assistants in mainstream schools.

It should be seen as every child's entitlement to be included in their local mainstream school whatever their needs. We should be working towards functional integration. Social and locational integration are in danger of exacerbating prejudice even more than segregated schools. Exclusion should be seen as a form of discrimination.

Section 2 of the 1981 Education Act 'establishes the principle that all children for whom the L.E.A. decide to determine the special educational provision to be made (and accordingly to maintain a Statement under Section 7 of the Act) are to be educated in ordinary schools, so far as is reasonably practicable, and are to associate in the activities of the school with other children.'<sup>16</sup>

Each local education authority should have a clear statement of its policy on integration, developed in consultation with parents and professionals, as part of its overall policy on special education.

Parents of children with special educational needs should have the same entitlement as parents of non-disabled children to state their

preference as to which school they wish their child to attend. This entitlement should be stated in local education authority policy and all schools encouraged to adopt it in their policies.

Education is going through a period of turbulence at present with the introduction of opting out of schools, local management of schools, league tables, and the national curriculum. Each of these changes is likely to put barriers in the way of greater opportunities for disabled children to be included in mainstream education. These difficulties will have to be faced and ways round them found. *Getting the Act Together*<sup>17</sup> gives guidance on how this might be done.

### **Under fives**

Every child with special needs should be entitled to experience group learning with other children of the same age who do not have special needs.

There is a range of ordinary local provision which pre-schoolers without disabilities use: nursery schools, day nurseries, mother and toddler groups, play groups, family centres. Many of these are now including children with disabilities.

Child Development Centres, Units and Teams often do assessments in conjunction with these ordinary provisions. Resources now put into segregated pre-school provision should be used to extend the support for disabled children in mainstream provision.

If children have been included in mainstream pre-school provision, by the time they come

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<sup>16</sup> D.E.S. Circular 8/81

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<sup>17</sup> Audit Commission and HMI 1992 *Getting the Act Together* HMSO: London.

to school age, their parents are more likely to expect their children to go to mainstream school with their brothers and sisters and other local children.

### **5-16 years**

Mainstream schools should be encouraged to adopt policies which stress the importance of including all children no matter what their disability. Each mainstream school should be seen to take responsibility for serving all children in its area. Every child should have the opportunity to be enrolled at the local neighbourhood school they would expect to attend if they were not disabled, even if they attend elsewhere. This would locate the responsibility for the child's education in the most appropriate place.

As every child has entitlement to the national curriculum every school should be flexible enough to accommodate a wide range of difficulties. All schools should be preparing students for adult life whether they have special educational needs or not.

Classroom assistants should be employed to provide the extra help which teachers may need to ensure that each disabled child's needs can be met in mainstream school. There is a danger of them acting as a barrier to growing relationships so they need to be aware that one of their primary roles is to facilitate relationships, not get in the way.

Children should be included in all aspects of school life as far as practicable.

At 13+ each child with a disability should take part in planning for their transition to post 16 opportunities. This requires a co-ordinated effort which involves all the agencies which provide post 16 services, together with the school.

### **Further Education**

Every learner should have the opportunity to move on from school to college at 16 years. At college they should use the ordinary resources available to other students with the support that they need: student services, mainstream classes, lecturers and tutors. Special needs should not be a subject in which students are enrolled, although there will be a need for learning support co-ordinators or tutors to guide the development of inclusion in colleges.

Each college should have a statement of policy affirming inclusion.

### **Transition**

Each child or student may go through several transitions within the education system: entry into pre-school provision, transfer to primary school, transfer to secondary school, leaving school at 16+ for further education college or employment or other day activity.

At each transition point there should be information on all the options available given to the family so that they are able to make informed choices. At 13+ every young person should be reviewed and future possibilities explored. This review is an opportunity to alert services of needs a learner may have on leaving school.

Many districts are now providing information packs listing services which might have something to offer school leavers, jointly prepared by all the agencies involved. These should be available to every family<sup>18</sup>.

Gathering all the relevant information for families will require agencies to collaborate

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<sup>18</sup> For further guidance on transition see Department of Health 1991 *The Children Act 1989 Guidance and Regulations Volume 6 Children with Disabilities* HMSO: London

with each other and with schools in ways that often has not happened before.

Close liaison is needed between providers on each side of each transition. This will enable the providers at the earlier stage to be aware of what they are preparing the student for at the next stage. They will then be able to make sure that what they offer is relevant to the learner's future career and life opportunities.

Co-ordination will be needed to ensure that the transitions from the various children's to adult services are when most appropriate for the person. They should not generally occur at the same time (e.g. education, health, place to live).

## Health Gain<sup>19</sup>

Though people with a learning disability are affected by the same health problems as the general population, they may experience a greater variety and number of health problems and these may occur more frequently. Ill health in people with a learning disability is often masked, and they may have additional medical conditions which arise from the underlying impairment.

People with learning disabilities often do not get the health care they need. Barriers to access need to be removed.

Health purchasers and providers will need to review what is required to meet the *health*

*care* needs of people with learning disabilities<sup>20,21</sup>.

Base-line information will be needed for the targets below against which to measure progress in service provision.

### Overall Goals

- to reduce avoidable premature deaths
- to reduce preventable morbidity
- to achieve measurable improvements in health status
- to support developments that maintain the health of carers.

### The NHS Must Help Make Social Integration a Reality

#### *Health Gain Targets*

- Ensure every person with a learning disability no matter how impaired should have a means of communicating effectively.
- Ensure that no one with a learning disability has:
  - an unmanaged refractive error
  - an untreated hearing deficit
  - an unassessed combined visual and hearing deficit.

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<sup>19</sup> This section draws on the following report to which further reference is recommended for detailed consideration: Welsh Health Planning Forum, 1992, *Protocol for Investment in Health Gain - Mental Handicap (Learning Disabilities)*, Welsh Office: Cardiff.

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<sup>20</sup> See NWRHA 1993 *District Services Components for People with a Learning Disability: A Guide for DHA/FHSA Purchasers*.

<sup>21</sup> See also NHS Management Executive 1992 *Health Services for People with Learning Disabilities (Mental Handicap)* HSG(92)42.

### **Service Targets**

- Health purchasers and providers, Family Health Service Authorities, social and education services should work with people with disabilities and carers to develop methods of assessing consumer satisfaction which are valid and reliable.
- In partnership with social services and local education authorities, health purchasers should develop service specifications which require the education and training of carers and staff living and working with people with a learning disability in understanding their communicative competence and in augmentative communication techniques.
- In partnership with ophthalmic opticians, audiometricians and specialists in deaf-blindness, health purchasers and providers and Family Health Service Authorities should ensure that clear policies exist to determine the prevalence of visual defects, hearing defects and combined visual/hearing defects among people with a learning disability, including encouragement of regular sight and hearing tests and ready access to the special techniques for the management of the deaf/blind.

### **The NHS Can Do More to Promote and Maintain the Health of People with a Learning Disability**

Carers including care staff, should receive guidance on observation and recording to provide information that may be of value to GPs or other health workers.

GPs should have protocols of care for each person with a learning disability defining regular checks, investigations needed and follow-ups. It should be possible for check-

lists to be drawn up of things to be specifically looked for at regular review for most conditions.

Support workers need appropriate guidance on promoting health and hygiene, fitness, diet, weight, lifting and handling.

### **Health Gain Targets**

- Ensure no child attains age five with an unidentified or unassessed learning disability.
- Ensure no one with a learning disability suffers from untreated hypothyroidism.
- Reduce the number of people with physical and psychological side effects of psycho-tropic medication.
- Reduce the proportion of people with a learning disability classified as overweight or obese.
- Reduce the prevalence of over-activity in children under nine with learning disabilities.
- Reduce avoidable loss of mobility among people with a learning disability.
- Reduce the incidence of challenging behaviour.
- Ensure no one with a learning disability suffers from untreated dental problems.

### **Service Targets**

- Health purchasers should through their service specifications ensure that all children under five suspected of having a learning disability have a comprehensive developmental and physical assessment

- by a community paediatrician and a community paedodontist, with a full range of multi-disciplinary support including Social Services.
- Health purchasers in service specifications and Family Health Service Authorities should require implementation of the guidelines of the Royal Colleges on the prescription of psycho-tropic medication, and audit approaches should be promoted to ensure practice is based on these and clearly recorded in the notes. Purchasers might also consider requiring providers to monitor the extent to which psycho-tropic medication is prescribed as a chemical restraint.
  - Directors of Public Health should be asked to review the additional health risks of people with disabling syndromes and determine priorities for regular monitoring where this could lead to preventative interventions(e.g. diet and the risks of passive smoking in service environments).
  - Health purchasers through service specification and Family Health Service Authorities should ensure that all people with Down's Syndrome have a yearly thyroid function test.
  - Health and other purchasers should through their service specifications promote interventions and associated monitoring procedures for preventing and responding to major challenging behaviours.
  - Health purchasers should through their service specifications ensure access, where appropriate, for people with a learning disability and their relatives to genetic counselling.
  - Family Health Service Authorities in consultation with their general practitioner and general dental practitioner contractors and specialists, such as paediatricians or specialists in learning disabilities, should examine ways to offer yearly health consultations to people with a learning disability and their relatives or carers, covering all aspects of health, including both assessment and advice.
  - Since at least half of people with severe learning disabilities also have epilepsy they should receive special attention so that a firm diagnosis can be established and the seizure type can be specifically identified. Only then can the optimum approach to management and treatment be identified. This will require referral to an appropriate specialist who is interested enough to work through what is needed.
  - People with a learning disability should be fully included in the Health of the Nation programme having the same investigations, guidance and interventions available through this programme as the rest of the population.
  - General contracts for hospital care should include explicit reference to people with learning disabilities and other major disabling conditions. This is to enable them to be treated appropriately, in accordance with the other principles and values mentioned in this document, when they go into hospital for medical investigations or treatment.

## **People with a Learning Disability Have a Right to Co-ordinated Health Care**

If people with learning disabilities are to receive the health services they require they will need vigorous representation whether from community nurses, senior clinical medical officer, consultant in learning disabilities, or other. This advocacy role should be clearly identified.

### **Health Gain Target**

- Ensure no deterioration in:
  - behaviour
  - physical health
  - mobility

especially during the period between ages 16 and 21, when people with a learning disability move into adulthood, as a result of entering different services.

### **Service Targets**

- Health purchasers and Family Health Service Authorities should through service specifications ensure a seamless transition in care across thresholds:
  - child to adult
  - adult to elderly
  - community to hospital
  - hospital to community

with an individual nominated to handle the transition in each case.

- Family Health Service Authorities and social services departments should liaise

to ensure that GPs have the name of the key worker for each person with a learning disability on their list and that the key worker knows of the GP.

- Health and other purchasers through service specifications should ensure that:
  - information on services is readily available to people with a learning disability in a form they can understand
  - assessment for psychiatric morbidity is part of the assessment for people with learning disabilities.
  - people with a diagnosis of mental illness and learning disability, particularly people with mild or moderate learning disability, should have access to generic psychiatric services and specialised services
  - there is a co-ordinated approach to meeting the needs of those with multiple problems
  - those who need an individual plan have one.
- Health purchasers are required to make available such health expertise as is necessary for the local authority to discharge its duties under the community care legislation<sup>22</sup>. An essential element of a service is provided by psychologists, speech therapists, occupational therapists, and nurses who are employed by health services but whose work cannot easily be pigeon holed in terms of health care.

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<sup>22</sup> See footnote 4.

## The NHS and Others Must Support the Health and Well-Being of Carers

### Health Gain Target

- Reduce levels of self-reported morbidity among carers.

### Service Target

- Health purchasers should through their services specifications:
  - establish a written agreed policy on counselling and sensitive disclosure of diagnosis
  - ensure that where appropriate, parents who have a child with a learning disability are offered genetic services to allow identification of the cause of the disability and counselling.

## Forensic Services

The number of people served by forensic learning disability services is currently small. They are often unknown to health and social services.

Guidance on services for people with learning disabilities who have offended against the law has been provided by the Reed Committee<sup>23</sup>. They should be cared for:

- with regard to the quality of care and proper attention to the needs of individuals
- as far as possible, in the community, rather than in institutional settings
- under conditions of no greater security than is justified by the degree of danger they present to themselves or to others
- in such a way as to maximise rehabilitation and their chances of sustaining an independent life
- as near as possible to their own homes or families if they have them.

In addition:

- Local agencies should consider jointly practical ways of raising the service profile of offenders with learning disabilities.
- Court diversion and assessment schemes should develop effective links with local learning disability teams and, where possible, team members should be encouraged to contribute to schemes, possibly on a rota basis.
- Agencies working with children with learning disabilities should develop a co-ordinated range of specialised services, sensitive to the wishes of parents and children alike, to meet in the round the needs of those who develop behavioural difficulties.
- Agencies should develop a joint approach to ensuring that adolescents with learning disabilities who offend or appear to be at risk of offending have access to a range of general and specialised services suitable for their age and stage of development and that they do not get drawn unnecessarily into the criminal justice system.

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<sup>23</sup> Department of Health & Home Office 1992 *Review of health and social services for mentally disordered offenders and others requiring similar services:*  
 a) *Final Summary Report*  
 b) *People with Learning Disabilities (Mental Handicap) or with Autism*  
 DoH: London.  
 Further reference should be made to these reports for detailed consideration.

- Local multi-agency groups for mentally disordered offender services and area committees for the criminal justice system should provide a clear focus for, or maintain effective links with, relevant services for people with learning disabilities.
- Agencies should develop joint plans to identify and provide for the specific needs of people with mild to moderate learning disabilities, including in particular those who offend or are at risk of offending.
- Effective links should be maintained or developed between learning disability, general psychiatric, forensic psychiatric and child and adolescent psychiatric services.
- Health authorities should consider the particular requirement for skilled nurses

to work with offenders with learning disabilities and others requiring similar services. They should address also the ways in which forensic psychiatric, general psychiatric and learning disability nursing relate to each other.

- Agencies should take account of the specialised and varying needs of offenders with autism, including the importance of links with other services that may be required.
- Training should be available to the police to recognise when a person may have a learning disability.

Special hospitals currently serve a small number of people from the north west. Arrangements should be made to bring them all back to local services and prevent any further admissions to special hospitals.

## Appendix 1: Principles from *A Model District Service*

### (a) Basic Axioms

**People with learning disability<sup>24</sup> have the same human value as anyone else and so the same human rights.** People with learning disability have often been regarded as second class citizens or even outcasts, not worthy to be treated as full citizens with full rights. They have been denied the range of opportunities available to other people. This denial is wrong and unacceptable.

**People with learning disability are developing human beings and services should assist them towards the greatest independence possible.** Many will not become fully independent but the aim is the maximum degree of personal development and independence possible. People with learning disability have been consistently under-estimated in the past. Much is known about designing environments to facilitate personal development. Denial of the opportunity to grow and develop constitutes an injustice. The expectations of all concerned must be raised so that people are actively challenged to develop towards independence. This requires a great investment in training and education of staff, relatives and public so that the knowledge and skills which are already available can be spread more widely.

### (b) Extract from the 1971 United Nations Declaration on the Rights of Mentally Retarded People<sup>25</sup>

The person with a learning disability has, to the maximum degree of feasibility, the same rights as other human beings.

The person with a learning disability has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.

The person with a learning disability has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest extent of his capabilities.

Whenever possible, the person with a learning disability should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If use of residential services becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.

The person with a learning disability has a right to a qualified guardian when this is required to protect his personal well-being and interests.

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<sup>24</sup> The terminology has been updated. No other changes have been made to this extract from *A Model District Service*.

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<sup>25</sup> See International League of Societies for the Mentally Handicapped (1978) *Step by Step: Implementation of the Rights of Mentally Retarded Persons*.

The person with a learning disability has a right to protection from exploitation, abuse and degrading treatment. If prosecuted for any offence, he shall have a right to due process of law with full recognition being given to his degree of mental responsibility.

Whenever a persons with a learning disability are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the person with a learning disability by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.

### **(c) Principles of Service Design**

#### **(i) Fundamental Principles**

All the following principles which are derived from the above axioms are naturally closely inter-related and inter-dependent. Their most general statement is embodied in the principle of normalisation, a simplified version of which is given first.

**The use of ordinary means which are valued in the local community in order to enable people to live ordinary lives.**

People with a learning disability of all ages should be regarded as members of the public, usually living at home or in ordinary accommodation in the community, and as entitled to both general and specialised medical, paramedical, educational and social services as are their fellow citizens. These services should be closely co-ordinated and designed to respond flexibly to gradually changing individual needs.

**The status of people with a learning disability should be enhanced by services, both by what is done and the ways it is done.** Their low status is the main reason why they receive 'Cinderella' services. People who are more highly valued have more doors opened to them. Raising status is therefore an essential feature implicit in the recommendations which follow.

**People with a learning disability are individual human beings with their own abilities, preferences and needs.** Being categorised and labelled can lead to regimentation and lack of attention to personal needs.

#### **(ii) Service Principles**

**People with a learning disability should not be segregated from the rest of the community in work, education, recreation or where they live.** If the aim is independence, opportunities for learning to live in contact with non-disabled people must be available. Conversely, non-disabled people may have to learn skills to live alongside disabled people.

**General resources available to the rest of the community should be used in ordinary settings as far as possible.** The practical implications of this principle will be one of the major challenges for services to address. Extra help may be needed to facilitate the use of these general services.

**Special provision should be available to meet needs which cannot be adequately met by ordinary means.** Every effort should be made to use ordinary resources first. Only when it is clear that they are inadequate should special means be sought. Such special provision should be tailored to a person's individual needs. Where special

provision is made, the least restrictive alternative should be chosen.

**The risks involved in change and development have to be recognised.**

**Unnecessary exposure to risks and over-protection from risks are both unacceptable.** Risks have to be judged and ways found of reducing them without restricting a person's development and opportunities for wider experiences. This requires knowledge and skill on the part of those concerned as well as consultation with clients, relatives, staff and managers so that all involved are familiar with the issues, as far as possible.

**People with a learning disability should be involved in decisions which affect their lives, as far as possible.** This also means learning to choose. It requires that alternatives are available, and teaching to assert preferences and rights.

**Service consumers, including disabled people and their families should be directly involved in planning services at all stages.** Service providers are often reluctant to work closely with service consumers. The closer the involvement of consumers the greater the likelihood that their needs will be met.

**Services should support the social networks which people with learning disabilities have already established, whether these are the networks of family, friends, neighbours, schools, clubs or work.** They should not supplant them. Continuity in personal relationships is extremely important. Residential services have often served to disrupt relationships.

**Services must be easily accessible.**

Consumers must have information readily available about services and assistance in

using them if necessary. Barriers to access must be removed. Where services are delivered by different personnel or agencies there must be no hindrance to access when needed. To consumers, services should be transparent and seamless.

**Services should be local and comprehensive. They should provide for all people with a learning disability and their families who live within each district or who wish to live in the district.**

**Services must be effectively co-ordinated so that providers and staff are able to meet needs in the most appropriate ways.** Co-ordination, which is a central problem for complex community services, must receive high priority in planning.

**Educational development must be pursued for all levels of staff.** Since many of the components of the model service outlined below are relatively new and progress in service development is taking place quickly, a heavy investment in staff training is required. It is desirable that multi-disciplinary training is pursued wherever possible.

**Quality safeguards are required so that the highest standards of service are sought and maintained.** Consumer involvement in planning, advocacy and an active staff training programme are essential. Monitoring, both internal and external, together with mechanisms for service systems to respond to reports in an adaptive way is also required.

## Appendix 2: Summary of Recommendations from *A Model District Service*

### (a) Principles

1. Services should be local and comprehensive.
2. Services should be designed in accordance with the principle of normalisation.
3. Services should be designed to meet the needs of each person with a disability<sup>26</sup> in the most appropriate and effective way.
4. Consumers of services must be represented in service planning e.g. by parents or guardians.
5. Planners must consider alternative patterns of service not dependent on the use of special buildings.

### (b) Ways of Meeting Needs

6. Individual programme plans should be written for each disabled person based on multi-disciplinary assessment.
7. General resources should be used wherever possible and help provided to ensure their fullest use by people with a learning disability and their families.
8. Specialised services are needed to meet special needs which cannot be met by using general resources. These include domiciliary services, day services (education and work) and alternatives to the parental home.
9. Specialised services should gradually limit the range of needs which they attempt to meet as clients begin to use more general services.
10. Support for parents of children should be provided to enable children to be cared for in

their own homes as far as possible. Where alternatives are needed, fostering and adoption should be available and small staffed homes for those who cannot be so provided for.

11. On reaching adulthood, clients and their families should have choices of accommodation, alternative to the parental home, available.
12. Accommodation should be in ordinary domestic housing dispersed throughout the community, with the degree of supervision appropriate to each person's needs, provided and organised in clusters based on neighbourhoods.
13. Housing should not, as a general rule, be purchased by health and social services but provided by housing associations and authorities.
14. Districts should aim to develop 10 new long term residential places for adults per 100,000 total population each year.
15. Short term care and sitting arrangements, both planned and emergency, should be provided for all people with a learning disability in their own neighbourhoods, mainly based on family placements. A staffed house could be used should the need arise.
16. The role of Adult Training Centres will need to be re-thought over the next few years as education authorities make more provision<sup>27</sup> in adult and further education services, as self-care skills are taught in the home and as volunteers facilitate the use of community leisure facilities in the evenings and at weekends.

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<sup>26</sup> The terminology has been updated. No other changes have been made to this extract from *A Model District Service*.

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<sup>27</sup> There is concern in 1993 that adult education in some areas is being cut.

17. Health input to day provision should be subsidiary. The health service should not be a major provider of day services but be fully supportive of day services.
18. Operational policies are required which encourage client development and recognise the risks involved. Consumers, staff and authority members must be aware of the issues.

### **(c) Organisation**

19. A joint body should be established between health authorities, local authorities and voluntary bodies, to exercise planning and co-ordination of services for people with a learning disability and their families in each district.
20. In each district, a group of officers should be brought together, from the various authorities serving people with a learning disability, to form a team to organise the delivery of the local learning disability services for adults.
21. Services for children with a learning disability should be co-ordinated by a District Disability Team which should additionally include social work, nursing and psychology specialists in learning disability, based in a Child Development Centre within the district.
22. Professional staff working directly with adults with learning disabilities should be brought together to work as teams.
23. In areas with significant ethnic minority populations, continued efforts must be made to recruit staff (especially social workers and community nurses) and volunteers from those populations to work with people with a learning disability and their families.
24. Volunteers have an essential part to play, especially in advocacy on behalf of vulnerable people who may have difficulty asserting their rights.
25. Regional and sub-Regional services should be run down as local services develop. Any

services which require clients to go outside their district should be carefully reviewed.

26. Dates must be agreed beyond which people will not be admitted to learning disability hospitals.
27. Plans are required at Regional and local level on day provision for the long stay hospital residents to be resettled over the next 10 years.
28. Regular internal and external monitoring are required to safeguard the maintenance of high standards of service practice.

## Appendix 3: A Charter for People with Learning Disabilities

- Standards and charters applying to other people shall also apply to people with learning disabilities.
  - Services will ensure that each person is treated as a full and valued member of their community, with the same rights as everyone else and with respect for their culture, ethnic origin and religion.
  - Services will be individually-tailored, flexible and responsive to changes in individual circumstances and delivered in the most appropriate local situation.
  - Services will strive to enable people to live in ordinary homes, and enjoy access to services and facilities provided for the general community.
  - Services will be provided by appropriately trained, qualified and experienced staff who will help the people they serve to develop fully in all aspects of their lives.
  - Services will be delivered in the least restrictive manner capable of responding to individual needs.
  - Services will strive to continually improve, using the latest research to provide the best treatment, care and support.
- (This charter is based on:  
Department of Health 1993 *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs*. Report of a Project Group chaired by Professor Jim Mansell).