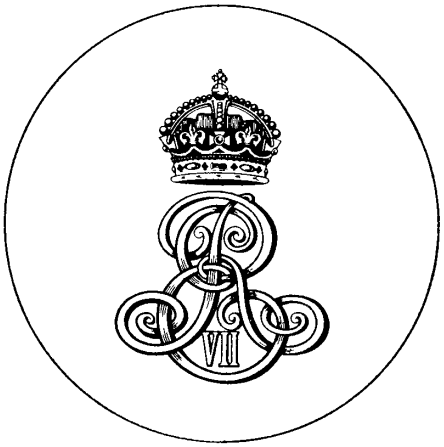

ISSUES FOR HEALTH AND LOCAL AUTHORITIES IN LONDON

POLICIES FOR COMMUNITY–BASED MENTAL HANDICAP SERVICES

BACKGROUND PAPER BY ALISON WERTHEIMER

FOR A CONFERENCE HELD ON 14 OCTOBER, 1982

AT THE KING'S FUND CENTRE

KFC 82/188

INTRODUCTION

This briefing paper has been prepared for a conference being held at the King's Fund Centre for health and local authorities in London. The aim of the conference is to examine issues related to policies for community-based mental handicap services.

The assumption throughout this paper is that it is both desirable and possible to provide locally-based services for mentally handicapped people which offer them normal patterns of life within the community.

In the current financial climate and with an inheritance of large hospitals situated mainly outside London, the development of local services presents a major challenge to health and local authorities. The conference will provide an opportunity for participants to hear about some of the local services already being developed and will look at some of the key issues involved.

This paper has been prepared in five sections:

(1) National policy developments in mental handicap in the 1980s

(2) Information on current mental handicap services for London, together with a brief financial note

(3) Principles and objectives for a locally-based comprehensive service

(4) Discussion of key issues relating to the development of local services

(5) List of references and other relevant reading material

1. NATIONAL POLICY DEVELOPMENTS

1.1 In December 1980, the government published its review of mental handicap services in the 1970s[1] and announced a series of measures intended to improve services in the following decade. 'Progress, Problems and Priorities', as the title suggests, indicated that the government felt some progress had been achieved in the previous decade (particularly in the development of local authority day and residential services), but that significant problems remained, especially in relation to the running down of long-stay hospitals. The setting of priorities was the weakest part of the review; the government merely endorsed the principles of the 1971 White Paper, Better Services for the Mentally Handicapped, and stressed the need to continue building up services at a local level; it was less clear about the future of the long-stay hospitals.

1.2 The most important of the measures announced at the end of 1980 was the proposal that ways should be sought to increase the flow of resources from the largely hospital-based services into local authority community-based provision. This, the government hoped, would enable more mentally handicapped people (as well as mentally ill and elderly people) to move out of long-stay hospitals into the community, A Green Paper,' Care in the

Community' was published in July 1981[2] and, following consultation, the government announced its decisions one year later: health authorities are to be encouraged to make annual payments to local authority social services departments for individual people moving out of hospital into the community and the maximum period for NHS support of jointly financed projects is to be extended from 7 to 13 years. However, no new extra finance is to be made available and successful initiatives are likely to depend on local goodwill and a willingness to collaborate.

1.3 A further government initiative was the '£ for £' scheme, launched in 1981 by a joint circular, 'Helping to get mentally handicapped children out of hospital'.[3] The DHSS is making £1 million available over 4 years by grants to voluntary organisations who can match £ for £ the government's contribution. It does not aim to replace the need for statutory provision but will enable some voluntary organisations to provide homes in the community for children who would otherwise remain in hospital. However, this initiative will also affect both health and local authorities whose services such as education and primary and specialist medical care these children will still be requiring whilst living outside the hospital.

The National Development Group for the Mentally Handicapped, set up in 1975 to advise the government on policy issues, produced a series of useful publications before it was wound up by the present government in 1980. Five pamphlets setting out detailed advice were produced covering such issues as adult day services, school-leavers and ways of making improvements in hospital services. The Group's final publication was a Checklist of Standards for use in monitoring services.

The National Development Group has a successor in the Independent Development Council for People with Mental Handicap, established in 1981 at the instigation of the leading national voluntary organisations and with the support of the King's Fund Centre. In its first year, the IDC has produced a paper commenting on 'Care in the Community', published a short guide to the elements of a comprehensive local service and initiated discussions with the DHSS and with district health authorities.

Individual health and local authorities have also produced some useful plans in the last year or two. A development group working in the Guy's District of South London has written a comprehensive and detailed plan for local services in the district.[4] Further afield, an excellent example of joint planning was undertaken by Newcastle City Council and the (former) Newcastle Area Health Authority which produced their plan in 1981.[5]

2. CURRENT MENTAL HANDICAP SERVICES FOR THE LONDON AREA

2.1 At the end of 1981 the London Health Planning Consortium published a study of mental handicap services in London.[6] The information in this section of the briefing paper draws heavily on this work.

2.2 General level of provision

The overall number of mentally handicapped adults and children receiving residential services from health and social services authorities in the four Thames Regions is somewhat higher than the national average, although the general trends in the rate of development are not dissimilar. The 16,000 health service beds in the Region comprise about one third of the total NHS mental handicap provision in England.

2.3 Balance of provision between the NHS and local authorities

Although the level of local authority provision continues to increase, the balance of provision within the Thames Regions is significantly more biased towards hospital accommodation than the rest of the country.

2.4 Siting of health service provision

The Thames Regions have 18 large mental handicap hospitals and 11 of these admit significant numbers of people from the London area. In addition, many of those who form the current long-stay population of these hospitals were originally admitted from the London boroughs. There are still some cross-Regional flows with residents of three London boroughs (Lambeth, Islington and Haringey) being admitted to hospitals outside their Region. Inner London has only a handful of NHS mental handicap beds and over 70% of those in the outer areas of London are concentrated in three large hospitals:
St Lawrence's, St Ebba's and Queen Mary's.

2.5 Local authority homes and hostels

At 31.3.1980 (most recent figures) Inner London authorities were providing 404 places in their own staffed homes and hostels for mentally handicapped adults and children although they used a total of 970 places - the remainder being in the private and voluntary sector - see para 2.6 below. Outer London boroughs had 825 places in their own homes and hostels and had a total of 1552 places available to them.

2.6 Use of voluntary and private provision

Just over half the residential places used by London's local authorities are in private and voluntary homes. This compares with a national average of one quarter. But even more importantly, many of these homes are outside the London area. Thus significant numbers of mentally handicapped adults and children are being cared for at a considerable distance from their own families and communities.

2.7 Day services

Nationally, the number of places in adult training centres still falls far short of the 1971 White Paper targets. London is well below the national average for current provision and particularly in the inner London area the number of places has barely increased in recent years. Many adult training centres are now full and with very little throughput it is becoming increasingly difficult to find day places for school-leavers. There is a particular shortage of places in special care units for more severely handicapped people. Six of the 13 Inner London boroughs have no places for people requiring special care and only 13 of the 20 Outer London boroughs make any provision of this kind. In the whole of Inner and Outer London there are only 26 special care units with 320 places. (Figures for 31.3.1981)

2.8 Movement from hospital into the community

Nationally over 80% of hospital discharges are of short-stay residents (85% of them had been in hospital less than a month). The Thames Regions present a

siginificantly different picture. Short-stay admissions are at only about 40% of the national level although the actual length of stay for this group appears to be longer on average in the Thames Regions hospitals than elsewhere. The number of discharges for long-stay residents remains small. In 1978 (most recent available figures) only 178 people from Inner London and 190 people from Outer London were discharged after stays of more than one year.

2.9 FINANCIAL NOTE

2.9.1 This part of the briefing describes the financial position of London local authorities and of the four Thames Regions. The information is very brief and intended only as a background to the more specific discussion about mental handicap services.

2.9.2 NHS expenditure

Details of new cash allocations and manpower numbers were announced by the Secretary of State on 15th July 1982. As in previous years, the four Thames Regions are to be 'losers' under the RAWP system of re-allocating expenditure between the 14 English Regions. In addition all Regions are being asked to continue to contribute to their own expenditure by making savings from increased efficiency measures; the government envisages this as being in the order of .5% over the next two years.

2.9.3 Local authority expenditure

The government has shifted resources away from urban areas in favour of the shire counties. In 1979/80 London was receiving 17% of the total Rate Support Grant but two years later this had dropped to 13.4%. Between 1979/80 and 1981/82 London has lost up to £500 million, by a combination of reduced RSG settlements, further deductions for overspending and increased expenditure by the GLC and the ILEA. Reduced central government support has meant that local authorities are shouldering a much higher proportion of their total expenditure through rates etc; whereas in 1979/80 RSG met 34.2% of their total expenditure, this had dropped to 25.1% by 1982/83.

3. PRINCIPLES AND OBJECTIVES

3.1 Virtually all planning documents which relate to services for people with mental handicaps now include some general statements about the underlying philosophy on which the plans are based. But in many instances their inclusion seems to have been a matter of course and the reason for including them not fully understood. Subsequent plans do not always reflect the philosophies stated and are often totally inconsistent. For example, plans may begin with statements about affording mentally handicapped people a normal life in the community and then go on to talk about building new small hospital units or other institutional and segregating provision.

3.2 All policies and plans for mentally handicapped people reflect certain beliefs about the nature of mental handicap; for example, the hospitals reflect the view that mentally handicapped people should be living in segregated

settings where a health service regime prevails; the tendency to plan services on a 'group' rather than individual basis appears to run counter to the belief that all mentally handicapped people are individuals with individual needs.

3.3 This briefing paper offers the following general statements of belief together with subsequent service principles which stem from those beliefs (drawn up by the Independent Development Council for People with Mental Handicap):

Services for people with mental handicap should

- affirm an enhance the dignity, self-respect and individuality of mentally handicapped people who are people first and mentally handicapped second
- pay due regard to what people with mental handicap and their families want and be informed by their views
- enable people with mental handicap to share in and contribute to community life, including family life
- assist people with mental handicap to lead as normal a life as possible, where necessary providing extra help to enable them to do so

Services should be based on the following principles:

- A first priority should be prevention of avoidable handicap: all individuals should receive comprehensive health education in school; have access to genetic counselling; and receive optimum obstetric and neonatal care
- All people with mental handicap, however severe their handicap, should be able to get the help they need in their own area. They should not have to rely on services at a distance from their own homes which endanger family and community links
- The best place in which to bring up children is within their own family circle and this includes children who are handicapped. If the natural family cannot cope then good substitute families are the best alternative
- Families should be helped to provide care for members who are mentally handicapped. There should be a concerted programme of support for the family including systematic help to assist the child's development from earliest infancy and services tailored to enable mentally handicapped adolescents and adults to achieve independence
- People with mental handicap, including the most severely handicapped, should use existing general services wherever possible, with extra help as they need it. Excessive reliance on separate specialist services is both expensive and wasteful and serves to segregate people with mental handicap from community life
- People with mental handicap and their families should participate in the planning and running of services on which they may be dependent. Services which are not firmly based on the views and experience of people with mental handicap and their families are unlikely to meet their needs

- Large mental handicap hospitals divorced from local communities are not appropriate for the needs of people with mental handicap and their families and should not be seen as part of the future pattern of services. They should be replaced by locally-based services integrated within the life of the community, where existing staff can make best use of their skills

- Residential services should be small in size, maximum use being made of ordinary housing

- People with mental handicap should only be cared for in hospital if they are ill, when it would be appropriate for them to be admitted to local hospital facilities. Hospital personnel should be trained to help people with mental handicap as part of their normal workload, being able to call upon special expertise as needed

- As a first step, children and young people with mental handicap should not be admitted to mental handicap hospitals and those already there should be discharged to appropriate community facilities

4. KEY ISSUES RELATING TO THE DEVELOPMENT OF COMPREHENSIVE LOCAL SERVICES

This part of the briefing paper looks at the implications of the philosophy and objectives set out in the previous section and discusses how a local service can be developed which is consistent with these principles. It is hoped that by spelling out the key issues health and local authorities' members and staff will be able to plan and develop services which are consistent with modern philosophies of care.

4.1 The meaning of 'local' in local services

4.1.1 The word 'local' is frequently misunderstood and misused in relation to services for people with mental handicap.

4.1.2 The KFC paper 'An Ordinary Life' provides a useful discussion on the nature of local services; it suggests that the smaller the area served, the more likely it is that a service will relate successfully to that particular community's needs. It is also more than just a question of being easily physically accessible, although that is important too.

4.1.3 The Report on the Bloomsbury Project[7] takes the discussion a stage further; it describes in practical terms how, applying the principles from 'An Ordinary Life', a local service could be established in a part of central London with a total population of 21,000.

4.1.4 The NIMROD project in South Wales provides a practical example of where such a highly local service is being established; with a total population in the catchment area of 60,000 this is further subdivided for the purpose of service provision and management into communities of 15,000 each.

4.2 The size of new units of service (small is beautiful?)

4.2.1 Provision has always been made for mentally handicapped people in the past on the assumption that they will be served in groups - so many for a community unit, so many for a hostel, so many for a day centre. The end result is that people have been slotted into places in a large group rather than having their individual needs assessed; these needs should be the starting point for planning services to meet those needs appropriately.

4.2.2 In current planning documents from the Thames Regions, there are indications that health authorities are still planning provision on a large scale; for example:

- the North East Thames RHA is planning 6 25-bed community units and 3 60-bed specialist units[8];
- the South East Thames RHA is planning a 72-place 'residential village' in Bromley HD and a similar development for the Camberwell HD[9].

4.2.3 There are a number of reasons why mentally handicapped people are better served by making provision on a more individual basis using ordinary housing:

- Mentally handicapped people, it is widely accepted, should live a normal life like everyone else in the community; this should include living in the same sort of housing in the community as everyone else does
- Every individual needs a house to live in; this is a basic need and is separate from and different to other needs such as the need for care and support or for particular services
- Large clusters of mentally handicapped people living together are less likely to be easily socially integrated into the neighbourhood
- To provide for large numbers of mentally handicapped people living together more often than not means providing 'special' buildings; such buildings reinforce the 'differentness' of mentally handicapped people and these solutions are also usually very expensive (see 4.3).

4.3 Avoiding the use of purpose-built accommodation

4.3.1 Because mentally handicapped people have traditionally been seen as being 'different' or 'special' they have usually received services and housing in buildings which are different from where the rest of society lives: hospitals, community units, hostels ...

4.3.2 As mentioned above, this is also an expensive solution:

- £843,000 for a proposed 24-place residential unit with 60 day places attached (proposed pilot hospital scheme at Clayponds, Ealing)
- £6.2 million for a 72-place residential village at Crystal Palace in South London[9]; (for construction 1984-6);
- £580,000 for a recently completed 20-place hostel in the London Borough of Tower Hamlets

4.3.3 Provision of this kind makes it virtually impossible to provide a truly local service; in Crystal Palace, for example, there will not be 72 people in that neighbourhood who require whatever services a health service 'village' will be providing. Neither is it possible to meet the very different needs of 72 mentally handicapped individuals when services are provided in such a large grouping.

4.3.4 Purpose-built large-scale accommodation can deter people from exploring the wider use of generic services in the community which will help to integrate mentally handicapped people more fully. There is a general tendency for a range of services to accrue on one site (most notably at long-stay hospitals) but those planning services should be looking out for the sort of opportunities below:

- use of public housing, housing association stock or purchase of ordinary domestic-size properties;

- use of ordinary further education premises for young adult school-leavers and other mentally handicapped adults wishing to continue their education;

- provision of specialist health services such as speech therapy or physiotherapy in ordinary health service buildings used by the rest of the community such as health centres or clinics.

None of these examples is new; they are all being done in some areas but by no means everywhere yet.

4.4 Joint planning and finance

4.4.1 Achieving a successful joint planning system is a long and slow process in London as elsewhere. However, some developments in the provision of mental handicap services are beginning to show the results of collaboration: community mental handicap teams, specialist social work posts, joint mental handicap registers. There is no doubt too that the joint finance programme has had some impact on this area.

4.4.2 A recent study of joint planning in the London boroughs[10] has provided a number of useful pointers which are worth quoting briefly here:

- A comprehensive joint review of existing services can help both health and social services to draw up some agreed general directions and shared priorities for future developments; these reviews should include consultation at the grass roots level

- The development of a shared information base is important e.g. through a joint mental handicap register; this should go hand in hand with shared financial information so that there is an overview of client needs and available resources

- 1982 NHS reorganisation has removed the tier most closely involved with joint planning. Regions are too remote for most local authorities to relate to usefully and the study found that Regions were not particularly interested in resolving the difficulties inherent in joint planning exercises

- Collaboration succeeds best at local levels and where specific rather than global issues are involved; large issues which may involve divergent philosophies of care or which affect manpower levels and budgets significantly are more difficult to resolve

- Joint finance plays a useful role in establishing innovatory projects; it cannot, however, resolve major strategic problems such as the rundown of large hospitals.

4.5 The balance of NHS and local authority expenditure

4.5.1 Central to this issue has been the Green Paper,' Care in the Community' and the government's response announced last July. Government policy is seeking to speed up the transfer of long-stay hospital residents into the community. By extending the periods of support for joint funded projects from 7 to 13 years and by encouraging health authorities to fund social services by annual payments to local authorities the government also envisages local authorities increasing their expenditure on mental handicap services and providing a greater share of services.

4.5.2 There is a major imbalance at present between NHS and local authority expenditure. The health service spends roughly three times as much on mental handicap services as local authorities. However, establishing a system of comprehensive local services will mean more than just transferring money across to the social services. Mentally handicapped people in the community will be likely to use a range of other services including housing, education and primary health care. It is also likely to involve changes in the amounts of social security payments currently made to mentally handicapped people.

4.6 Relocating staff from the large hospitals

4.6.1 Relocation of services into more local settings and away from the large hospitals will involve relocating staff as well as mentally handicapped people. As the transition to a more local pattern of services is a gradual one, however, it should be possible to achieve some movement by the retirement and job changes of a proportion of existing hospital staff.

4.6.2 It is likely too that some hospital staff will wish to work in community-based services; over half the nursing staff in an OPCS survey undertaken for the Jay Committee of Enquiry said they would consider working in a local authority or voluntary home or hostel.

4.6.3 One of the most important considerations in planning the staffing of new provision, particularly for residential services, will be the skills and abilities needed by staff working in these settings. They are likely to be working with much smaller numbers of people and should be able to concentrate on developing particular skills to use with individuals with particular needs. In-service training will be of great importance here.

4.6.4 Pages 32-5 of 'An Ordinary Life' describe the staffing needs of a comprehensive local service, and for those particularly involved with the issue of relocating hospital-based staff this is very fully discussed in Chapters 4-6 of the Report from the Jay Committee of Enquiry.

4.7 Role of the voluntary organisations and of consumers

4.7.1 The government, in its recent pronouncements on mental handicap services, has stressed the important role of the voluntary sector as a service provider. London boroughs, as already mentioned, are particularly heavy users of the privately and voluntarily run homes and hostels - both for adults and children.

4.7.2 However, these 'voluntary' services should not be seen as in any way lessening the obligations of both health and social services to make further provision themselves, particularly since so many of the private and voluntary services used by London authorities are at a considerable distance away from the capital. They cannot be seen as part of a local service for London.

Voluntary organisations have a role to play in planning and developing new provision and monitoring current services. As advocates of mentally handicapped people, the voluntary organisations should be representing their interests and ensuring that their rights to services are protected. Increasingly too voluntary organisations will be in the business of encouraging mentally handicapped people to be their own advocates - through the growing number of self-advocacy groups at present mainly located in adult training centres.

4.8 The role of health and local authority members

4.8.1 Members have an important role to play in bringing about the sort of changes in service provision described in this paper. The establishment of local comprehensive services in London presents major challenges and the political commitment of members will be central to making it happen.

4.8.2 There are already some examples in different parts of the country where members play a central role in the development of services. In Newcastle, where the City Council and the (former) Area Health Authority produced a joint plan last year, the new management partnership will involve member (and officer) representation from both authorities (as well as representatives of parents and voluntary organisations).

4.8.3 But there is no single solution to the problems involved in running down the large hospitals and replacing them with local services; members will need not only to have the political commitment to backing change but they will need to be constantly involved in checking plans, monitoring developments and ensuring that services are consistent with the best modern principles.

5. REFERENCES AND OTHER READING MATERIAL

References

(1) Mental Handicap: Progress, Problems and Priorities: A review of Mental Handicap Services in England since the 1971 White Paper, 'Better Services for the Mentally Handicapped'; DHSS, 1980.

(2) Care in the Community: A consultative document on moving resources for care in England; DHSS, July 1981.

(3) 'Helping to get mentally handicapped children out of hospital': DHSS joint circular HC(81)13/LAC(81)9; November 1981.

(4) Development Group for Services for Mentally Handicapped People: Report to the District Management Team: Guy's Health District, January 1981.

(5) Mentally Handicapped People and Their Families: A Blueprint for a Local Service: Newcastle City Council and Newcastle Area Health Authority (Teaching); April 1981.

(6) Profile of Mental Handicap Services in London: London Health Planning Consortium, 1981.

(7) The Bloomsbury Project Report: A community service for people with mental handicap. Available from Department of Community Medicine, University College Hospital, London WC1.

(8) The Future Provision of Services for Mentally Handicapped People: A consultative document; North East Thames Regional Health Authority; July 1982.

(9) Planning Guidelines for 1982/3: South East Thames Regional Health Authority; July 1982.

(10) 'Barter and Bargains' by Howard Glennerster; Article in Health and Social Services Journal, 24 June 1982. Based on a study of joint planning in London boroughs over the last eight years by Glennerster et al.

Other reading material

The following were sent to conference delegates with this briefing paper and contain more detailed bibliographies:

An Ordinary Life: comprehensive locally based residential services for mentally handicapped people. King's Fund Project Paper No.24, Reprinted July 1982.

A Short Guide to the Elements of a Comprehensive Local Service for People with Mental Handicap: Independent Development Council for People with Mental Handicap; July 1982.

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