

Title pages

An ordinary life: comprehensive locally-based residential services for mentally handicapped people

Cover illustration by Anita Sutton showing a black ink line drawing of a small village with houses, shops, a hospital, a garage, and a church.

"Our goal is to see mentally handicapped people in the mainstream of life, living in ordinary houses in ordinary streets, with the same range of choices as any citizen, and mixing as equals with the other, and mostly not handicapped members of their own community."

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Inner front cover

King Edward's Hospital Fund for London is an independent charity founded in 1897 and incorporated by Act of Parliament. It seeks to encourage good practice and innovation in health care through research, experiment, education and direct grants.

The King's Fund Centre has a particular role in promoting advances in policy and practice in relation to problems of health and related social care. It offers a forum for informed debate, provides an information service and organises a range of activities designed to support local strategies for service development.

One important focus for the Centre's work in recent years has been the practical steps necessary to develop comprehensive community-based services for people with mental handicaps and their families. In parallel with the present paper, the Centre has published two further project papers:

Bringing Mentally Handicapped Children out of Hospital (Project Paper No.30, November 1981, price £1.25) describing the alternative services in the community required to relocate the remaining children and young people in hospitals; and *Better services for the mentally handicapped? Lessons from the Sheffield Evaluation Studies*. (Project Paper No.34, 1982, price £1 .50).

A series of complementary shorter papers is also being produced, including to date: *Short Term Care for Mentally Handicapped Children* (King's Fund Centre Discussion Paper, February 1981, 75p.) *The Portage Model of Home Learning Services* (King's Fund Centre Discussion Paper, February 1981, 75p.) *Mentally Handicapped People with Special Needs* (King's Fund Centre Discussion Paper, July 1982, 75p.)

All these papers are available from the Centre. Prices include postage and packing.
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Foreword - Progress towards 'An Ordinary Life'

The King's Fund Centre first published *An Ordinary Life* in February 1980. My original Preface described the background to this Project Paper and the ways in which the working group who prepared it hoped it might be used as a basis for developing current thinking and promoting local initiatives. Their expectations have since been more than fulfilled: the paper has been reprinted twice; there has been widespread and still growing interest in the ideas it contains; and the title itself has for many people become a shorthand way of symbolising the philosophy which should guide the provision of services for people with mental handicaps.

In this reprinting, the text of the original paper is unchanged. All its general arguments still seem highly relevant to the efforts being made across the country to improve existing residential services. In this Foreword, however, I have tried to summarise developments associated with this initiative. The working group (now extended to embrace a wider range of expertise and experience) has also contributed a new bibliography, including recent references which take the argument of particular sections forward or provide accounts of practical achievements. The original impetus to produce this paper came from the growing number of enquiries to the Centre from people seeking precise information about the different ways in which they might develop local services to people with mental handicaps. Enquiries were, and continue to be, received from workers in health, social services, housing and voluntary agencies, community health councils and parent organisations, often with a common interest in exploring better ways of providing the residential components of a comprehensive service.

In many places, the paucity of existing services and the shortage of resources is leading to a search for approaches which do not necessarily demand major building work. In other places, significant investments are being planned but local workers remain concerned that too much of this welcome input of resources is being channelled into conventional residential provision - either medium-sized hospitals or, at least until recently, purpose-built local authority hostels - when further search might have thrown up other options. Indeed, as examination, for example, of current NHS strategic plans reveals, many planning authorities show little evidence of learning from past experience. It is particularly ironic that plans for the 1980s and 1990s are imitating models of provision developed in the 1960s and 1970s after their originators have already moved on to better things. In Sheffield, for instance, the Evaluation Research Group pointed to major weaknesses in the services produced through the Government sponsored Development Project: accordingly the Joint Consultative Committee has recently approved a fresh strategy which, despite the heavy investment in new buildings over the last decade, seeks to make maximum possible use of ordinary housing in the community. In Wessex, the priority given to developing local mental handicap services is being sustained but some Districts are now aiming to base these services in adapted houses very much smaller than the 25-place units built previously. And although the ill-defined concept of 'community units' apparently advocated by the National Development Team now appears in many NHS plans, there are growing doubts about the appropriateness of such units for providing residential (i.e. 'home-making') services.

Reinforcing these trends, a variety of developments at national level have pointed strongly to the need for informed innovation. Most explicit is the philosophy and model of care advocated in the *Report of the Committee of Enquiry into Mental Handicap Nursing and Care*, published while this Project Paper was being prepared in 1979. The Government's subsequent endorsement of this philosophy, its concern to find financial mechanisms which speed up the transition towards Care in the Community and its specific commitment to bringing the remaining children and young people out of hospitals, have all added weight to this movement. And although the National Development Group has been abolished, the recently-formed Independent Development Council for People with Mental Handicap is

already showing that representatives of the main voluntary organisations and leading professional opinion are united in seeking to promote the development of local services which embody the principles of *An Ordinary Life*.

In 1979 when this initiative began, however, there was no well-documented British account of a comprehensive pattern of residential services based on domestic housing. Although several small-scale projects were beginning to put original ideas into action (of which perhaps the NIMROD project in South Glamorgan has since made most progress), we had to look to other countries for a working demonstration of what is possible - and here the achievements of the Eastern Nebraska Community Office of Retardation (ENCOR) seemed to offer particularly valuable lessons. As a start to filling this gap, therefore, the King's Fund Centre convened a series of small workshops to explore how local residential services which include aspects of the ENCOR model might be developed in Britain. (The main contributors to these workshops are listed overleaf.) Participants were particularly concerned to examine what would be involved in putting together practical information and advice for planners and providers of services. The first product of these meetings was this working paper, which provides an overview of the principles which should guide new residential services and the constituent elements of such provision.

The working group intended this paper to be no more than a beginning. They recognised that if further progress was to be made in improving mental handicap provision, it would be vital for workers in different localities to come together to learn from each other's experiences and establish means of mutual support. From discussion and debate it might then prove possible to refine and develop the ideas in *An Ordinary Life* and test them more fully in practice.

This has indeed been happening. The paper itself is becoming widely known. More than four hundred people have participated in conferences and workshops at the Centre where its suggestions have been explored, and other meetings have been arranged locally in some parts of the country. In addition to examining issues of policy and implementation, the Centre workshops have focussed on particular questions requiring more detailed attention: the roles parents can play in shaping the development of local services; the leadership members of health and local authorities can provide in a complex process of change; the ways of planning and monitoring community-based provision; the training which needs to be arranged for staff recruited to work in new kinds of services; and the services required to support *An Ordinary Life* for those clients with "special needs" who are often perceived as posing the biggest problem to existing services. In parallel the Community and Mental Handicap Education and Research Association has organised a series of more local training events, to clarify issues of service philosophy and help people develop skills in the systematic evaluation of plans and practices.

In connection with these activities the Centre is producing a set of more detailed working papers (listed inside front cover) so far covering the lessons to be learnt from the Sheffield Development Project, the steps necessary to bring the remaining children and young people out of hospitals, the principles which should guide the provision of short-term residential care and the individual programmes required to serve people with special needs. The Centre is also collecting documentation on operational policies and procedures produced locally (the operational policy for the council house in Northumberland which serves local children resettled from a ward in Northgate hospital, for example, and the guidance on formulating individual programme plans prepared by the Mental Handicap in Wales Applied Research Unit for the NIMROD service). Increasingly, too, interest is moving beyond residential components to consider the requirements of comprehensive local services consistent with the *An Ordinary Life* philosophy. This is reflected, for example, in the detailed planning document published by the Guy's health district and the elegantly-produced

paper of another local group on An Ordinary Life in Harlow. (See bibliography for references.)

In sum, since this paper was first published there has been a significant shift in the national climate favouring real community care, considerable further work on how comprehensive locally-based residential services can be developed, and some encouraging if still modest progress towards achieving such services in a number of localities.

However, the challenge remains enormous. Over forty-thousand people with mental handicaps still live in hospitals, while several thousand others are living with parents who are already into old age. Moreover, despite Government policies for Care in the Community, public expenditure constraints, particularly the severe pressures on local authority spending, will make development of appropriate services for these and other people an increasingly up-hill struggle.

Members of the working group which produced this paper remain keen to join with others to extend current thinking, strengthen the networks linking people engaged in innovation, and find ways of encouraging further local initiatives. So comments, enquiries and suggestions arising from this paper - addressed to the group's secretary, Joan Rush, at this address - will be very welcome. If it is possible to build on and extend the best of what is being attempted locally, it may well be that the next edition of this paper can be based wholly on British experiences of supporting people with mental handicaps in living An Ordinary Life.

King's Fund Centre
June 1982
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Introduction

Why did the authors of this paper come together in a working group to study the development of comprehensive local residential services for mentally handicapped people? A brief look at official policy over the past couple of decades, and at what has actually happened, gives the answer. Although government policy has, since 1959, urged a move towards community-based services for mentally handicapped people, the numbers admitted to mental handicap hospitals for long-term care in fact increased steadily during the 1960s. Since 1970, as the deficiencies of hospital provision have been publicly acknowledged, the numbers in hospital have gone down by about 1,000 a year. But this has been achieved mostly through reducing long-term admissions, particularly of children, and through deaths among the disproportionately elderly hospital population. The number of people who have moved from mental handicap hospitals to alternative accommodation in the community has been tiny. Only about 150 or 200 people a year have moved into local authority provision. Despite the occasional scandals about large numbers of people discharged to unsatisfactory accommodation in inner cities and run-down seaside resorts, the total number is unlikely to be above a thousand. There has been little increase in private and voluntary residential provision.

Meanwhile, significant amounts of money are going into improving and replacing existing NHS accommodation, with hospital units of 70, 100, or more beds as a favoured model. The Civil Service, the medical profession, the National Development Group and the Development Team all appear to favour the retention of some institutional provision. Their arguments suggest that 'some' services can be provided only in a hospital. But precisely what these services are and which mentally handicapped people need them is far from clear. In fact, decision-making is dominated by questions of resources. Local authorities are operating under severe political and financial constraints; the major share of the mental handicap budget rests with the NHS; mechanisms for transferring funds from the second to the first have, as yet, had only a peripheral effect. In this situation, little thought has been given to analysing patterns of need and clarifying the principles of a service geared to meeting that need.

Service planners who are looking for a comprehensive residential service which is responsive to need have three 'official' models to guide them:

1. The Wessex model provides residential services for severely handicapped people in locally-based hospital units of twenty or so beds which are sited in and serve specific catchment areas. Carefully specified management procedures have been independently monitored and shown to produce favourable results. But the size and location of the units means that they are not well integrated, physically, in local communities.
2. The Sheffield/Peterborough model provides living units for 16 children, 24 adults, sub-divided into smaller groupings, and combined to give hospitals of between 48 and 200 places. External evaluations suggest that these hospitals have developed some services which are clinically sound. But they share the old problems of social integration, and service patterns vary between them.
3. The 'community unit' model has been emerging from a series of papers by the National Development Group and Development Team. It appears to be an action-resource centre which may be temporary or permanent, providing services to adults or children, for a long or short period, living in or living out, with basic care or skilled professional support or administrative office accommodation - or any combination of these. The model may be administered by health or social services, but it is not comprehensive and the future development of a pattern of services based on 'community units' is not clear.

All these models have run into administrative problems which seem likely to be solved only when there are more resources and when health and social service administrators can work together in a more co-ordinated way. More fundamentally, though, we need a sharper analysis of needs and a clarity about key points of principle. So far we have neither. Until we have them, we shall go on providing 'units of accommodation', rather than 'services'. Provision will continue to be patchy, discontinuous and widely differing in quality. And the segregation of large numbers of mentally handicapped people from normal community life and family ties will continue.

So we saw a need to develop with others an alternative model for residential services and the King's Fund Centre was very willing to support these efforts. This working paper is the first step in that project.

Our goal is to see mentally handicapped people in the mainstream of life, living in ordinary houses in ordinary streets, with the same range of choices as any citizen, and mixing as equals with the other, and mostly not handicapped, members of their own community

The structure of the project

This working paper looks at the various 'problem areas' which authorities beginning to implement a comprehensive community-based service are likely to run into. Some will already have developed their own local solutions, but we have assumed a hypothetical authority which is starting from scratch so that we can show all the components of a comprehensive service. This authority will need first of all to develop a philosophy and model of care and to collect basic planning information. It will have to look at practical questions, like the components of a residential service and finance. It will have to look at organisational questions, like housing, staffing, management and monitoring and evaluation. It will have to master specific techniques like individual programme planning. It will have to tackle questions of inter-agency collaboration and create local strategies for change. In this paper, the working group has drawn together information and practical guidance in each of these areas. Wherever possible it has drawn on existing examples of good practice.

Our thinking has been guided by one very notable example of good practice. The Eastern Nebraska Community Office of Retardation (ENCOR) has its faults, but most of the eight members of the working group who have visited it agree that it comes closer to being a model of good practice than any other service we know. ENCOR is a comprehensive community service. That means it provides or obtains for the mentally handicapped citizens of Eastern Nebraska a comprehensive range of educational, residential, and vocational services. It aims to do this for all the people it is in business to serve: no-one is rejected as "too handicapped" or "too difficult." And it provides services in the areas where its clients and their families live, rather than taking clients away to service centres.

We have found many examples of good practice in the UK as well. We were particularly impressed by short-term care in Leeds and in Somerset; by Bamardo's residential services to children in Skelmersdale; by locally-based services in Wessex; by vocational services for adults in Newcastle. Each of these examples shows how the various components of a comprehensive, community-based service might be developed. Many other projects and schemes have elements of good practice in them, even though they fall down in other respects. Some residential communities, for example, provide a very high quality of life within their own confines, but are also restrictive, because they encourage total dependence on the immediate group and so make it hard for people to integrate into the wider community and take risks. Some hospitals provide very high-quality training and rehabilitation programmes, but because their residents live in large wards without a sense of personal identity and opportunities to make choices, much of the value of these programmes is lost.

We have found that devising a comprehensive community-based residential service is a very complex job. It isn't simply a matter of drawing together all the good practice we can find, because components of the service are still missing. Some aspects of the ENCOR system do not translate to a UK setting; Britain cannot provide all the components we need from existing services. So we have had to devise schemes which do not exist at the moment. We recognise that this brings difficulties, because we cannot point to examples of such schemes in action and because others will find it hard to envisage them. But we have enough confidence in the principles involved and in what practical experience has taught so far to say that our approach is possible and practical.

The sections on the different 'problem areas' which follow are open-ended. They need to be tested out with people working in the field and refined in the light of their experience. Members of the working group want to work with the King's Fund Centre, individuals and authorities to develop these ideas further and help put them into practice. This paper has already been improved as a result of comments made on an earlier draft, at two King's Fund Centre workshops. We hope that it will now be used in other people's conferences, training

programmes and planning seminars. We hope it will be used to build a network of support among people working in their own localities. It is, in the end, an invitation to service managers and planners to explore the resources which they, the Centre, and the working group, can together use to develop comprehensive community-based services for mentally handicapped people.

What is a residential service?

The term 'residential service' is, perhaps significantly, rarely used when people talk about provision for others who are mentally handicapped. In writing this paper, we have run up against some difficulties in finding the right words to describe what we are talking about. Even the word 'home', which conjures up such strong positive feelings for us all in our personal lives, has acquired some negative connotations in the context of welfare provision. There is nothing welcoming, secure or comforting about being 'put into a home'; yet our aim is to offer mentally handicapped people, no less than any citizen, the positive connotations of the word 'home'.

Discussions of earlier drafts of this paper have shown us, too, how different agency systems have given rather truncated meanings to general concepts. So a 'residential service', for some people, has to do with provision under Part 3 of the 1948 National Assistance Act, and automatically excludes housing. That is very far from the way in which we use the phrase; for us, the involvement of housing agencies is crucial. So a 'residential service' for other people may mean exclusively houses with live-in staff. Again, that is far from our meaning; for us, staffed homes are only one component of a residential service. 'A residential service in the community' brings its own complications because for some people 'community care' means exclusively the care provided by families for their handicapped member. Once more, we are using terms in very different ways; for us, community is a broader concept and mentally handicapped people have the right to choose among alternatives to their family home.

The problems are not just semantic. They are conceptual as well. 'Residence' is not often thought of as a service in itself. It is seen as part and parcel of some larger pattern of provision. So for years, mentally handicapped people have been brought into hospitals to receive specialised therapy and training. The function of nurses as 'home-makers' has been largely overlooked and the quality of home-life provided by them has often been very poor indeed - if compared to what any of us would seek for ourselves. The benefits of the expert skills available have often been far outweighed by the disruption of contact with family and community and the impoverishment of daily home life provided in these institutions. In the same way, residential special schools have focussed on educational needs and often provided a very poor substitute for home life.

We see the provision of a home-life as the central core around which many other services - training, education, rehabilitation, medical treatment - must be woven. 'Residence' is not simply something tacked on to specialised professional work. It is the very core of that work, and must be recognised as a service in itself.

Given the confusion about terminology which is to us quite fundamental, we thought it would be helpful to start with some definitions:

- A residential service aims to provide a home and home-life for people who cannot find these independently. It makes it possible for people to live in a home of their own. A residential service is a home-making service. It uses two kinds of resources. The first are material - the buildings in which people live and the things they use to make them places of comfort, privacy and security. The second are even more important - the people who staff the service and bring to it their home-making skills. People who work as home-makers have two kinds of tasks - 'doing' and 'teaching'. They provide the settings and things which are needed to make a home and where necessary they do the tasks of daily living for their clients. Some of these tasks are very personal and private, others less so, but they are all part of what our society takes for granted as home-life. The people who work as home-makers also help their

clients to provide for themselves what they need to make a home. They teach their clients to be more independent in the business of everyday living.

- A service is there to serve. It is its task to provide the right material and human resources. People who work for the service are the servants of their clients. That service is not just a collection of facilities and employees. It has a commitment to the people who are served, of the sort that parents, volunteers and others who are not paid for their work often show. A major task of the authorities which provide a service is to develop among their staff this ability to share their lives with the people they serve.
- Community is a very complex concept. It usually means a specific geographical area, but it also includes a loose sense that the people who live in this area belong together. One of the things which commonly binds a community is the range of basic and shared resources - streets and shops, banks, clinic and post office and pub. In urban areas a community may be small in size but large in population; in rural ones the reverse is often true. The community is also likely to be, for any individual, the place where he finds the people who are important to him - his family, friends, and acquaintances he meets regularly in everyday life.
- A neighbourhood is the area around a facility which is within reasonable travelling distance. It is much smaller than a community. A reasonable travelling distance will vary from place to place and with the forms of transport which are available. But a neighbourhood can usually be crossed in a maximum of fifteen minutes.
- A local or community-based residential service is provided within each community for the people who come from that community. Because communities are often very personal and hard to define, it is easier to plan local services. The smaller the catchment area and the more local the service, the more likely it is that it will also relate to the communities to which people belong. But a local service needs to be very flexible, to take account of the wide variations between communities and between different people's community networks. Often it will be very local indeed, and each family will have services available within its own neighbourhood.

Principles and practice in a residential service

This project is about practical changes in services to mentally handicapped people. But we believe that good changes can only be achieved by looking at the principles by which people are operating. That is why the first section that follows is about the philosophy of services.

The principles of our existing services are often very muddled. They are made up partly of written statements from government or local authorities, partly by professional workers. They consist partly of the historical traditions of services, partly of day to day solutions to problems, drawn up by staff, often without guidance. Much of our policy is unwritten, even accidental. At worst it is based on commonly-held fallacies and prejudices about mental handicap. What is certain is that all policies and every aspect of service provision, every day-to-day decision to provide or not provide a service, involves principles - even if the principle is simply that other groups are more important than mentally handicapped people. What is certain too, as Wolfensberger has shown, is that all policies for mentally handicapped people embody and reflect deeply-held social values and beliefs about the nature of mental handicap. This is true whether the policies are 'manifestos' and 'policy programmes', or whether they are just developed ad hoc by people who happen to be doing the job at the moment.

So we make no apology for setting out on this very practical project by explaining our philosophy. People who disagree with our values can then identify their points of disagreement. We believe, for instance, that mentally handicapped people, in common with everyone else, are developing human beings and citizens. People who disagree with us can produce evidence and argument to show that mentally handicapped people are not as we see them. We hope that people will examine our principles in some detail and ask themselves whether the service we talk about is the one they want to provide. If it is not, they might then spell out clearly their own principles and the way they would seek to put those principles into practice. In fact, there is likely to be less disagreement about principles than there is about achieving a service that is faithful to them. But it is only when principles are spelt out clearly and in detail that we can see at what point practical considerations or strategies for change begin to come into conflict with them and the ways in which we must try to modify these.

A philosophy for a residential service for mentally handicapped people

In setting out here our own principles, we are not seeking to impose any one set of standards or a particular way of life on mentally handicapped people. We are simply setting out our own values and beliefs about real choices and opportunities we think should be available. None of these principles stands alone. They need to be read together to understand the connections between them.

Fundamental principles

This paper is based on three key principles:

1. Mentally handicapped people have the same human value as anyone else and so the same human rights.
2. Living like others within the community is both a right and a need.
3. Services must recognise the individuality of mentally handicapped people.

Principle 1: Mentally handicapped people have the same human value as anyone else

Mentally handicapped people have the same rights and, as far as possible, the same responsibilities as all other members of the community. They also have the right to the additional help they may need to claim the common rights of the citizen. Although we do not reproduce here the different lists and definitions of the rights of mentally handicapped people, we hope readers will study these (for example, the United Nations *Declaration of the Rights of Mentally Retarded Persons*, 1971). Mentally handicapped people are commonly denied their rights, and the opportunities to which they also have a right, and are often unable to assert their just demands on their own behalf.

Those who serve mentally handicapped people have a duty to ensure that opportunities to live life to the full are available to them. Where mentally handicapped people lack the ability to claim their rights independently, it is the duty of those who serve them to claim on their behalf, assist in their claims and preserve their rights jealously.

Principle 2: Mentally handicapped people have a right and a need to live like others in the community

Living like others within the community is a right and a need. It is not a matter about which empirical judgements can be made. There can be no question of whether someone is 'able' to live in the community. It is the duty of services to ensure that all mentally handicapped people have the help they need to live in the community. Some may choose not to - as is their right as well. But until the services are available which enable everyone to live in the community, there is no choice, and rights are denied.

Living within the community is not only a right but a need. Mentally handicapped people need to live in the community because that is the only way that they can begin to be guaranteed their share in normal patterns of life. It is the only way they can learn from their non-handicapped fellows; it is the only way that their fellows can begin to learn from them. Only when they live as others do can mentally handicapped people be accepted as having equal value. Only by living as others do can they have access to the same privileges, services and responsibilities as others. Only by living with non-handicapped people can they have available the range of stimuli and models of behaviour which they need if they are to develop their potential to the maximum. It has been shown that mentally handicapped people develop skills much more rapidly when they live with non-handicapped people than when they live mainly or solely with other handicapped people.

It is only when mentally handicapped people live in the community that they can begin to be guaranteed the opportunity to make a full range of relationships. These range from the casually supportive relationships with shopkeepers and others who provide the cement to community life, to closer relationships with friends who share the same interests, to mutually supportive relationships between two people of opposite sexes or the same sex. All of us would recognise these relationships as a need in our own lives. They are no less so in the lives of people who are mentally handicapped.

Living in the community means more than being in a particular place. Mentally handicapped people also need special help, support, guidance and sometimes protection to enable them to enjoy the benefits of community life to the full.

Principle 3: Services must recognise the individuality of mentally handicapped people

Mentally handicapped people, like anyone else, have the right to behave as individuals, within the limits of the law, and to be recognised as individuals, with their own abilities,

preferences and needs. No one profession, no single type of provision, can meet the needs of all of them, and services must recognise this. Each has needs in common with many others, but equally each has needs which are particular and will change as time goes by.

Mentally handicapped people, their families and their friends, have important things to say about their lives and the services they need. All clients should have their needs assessed and, together with their families, participate in that assessment with professional experts and service providers. This team should jointly decide what services the client needs; a list of priorities and short and longer-term goals should be drawn up. There should be no consideration of either the cost or the availability of services before this has been done. The goal of the team is to assess the needs of the individual, not the services which are currently available. It is only when a programme is drawn up for the client, identifying priority needs and goals, and subject to regular and frequent review, that the services which cannot at present be provided should be identified (We call this the 'individual programme plan' (see p. 25). The Jay Report calls it the 'life plan'). This information will be important to planners who are working on the development of services, as well as to the future of the individual. It is only by following this pattern that service-providers can be sure that what they are doing is really tailored to the needs of clients.

Service principles

These are much more specific to the practical business of running a service. Here are some which stem from the examples of good practice we know; the list is not comprehensive:

1. All mentally handicapped people who have been assessed as needing a residential service have a right to that service. No-one can be denied that service because they are considered 'too old' or 'too handicapped', or because they have been living out of their own community. Locally-based residential services have the duty to be comprehensive.
2. Services should support the social networks which mentally handicapped people have already established, whether these are the networks of family, friends, neighbours, schools, clubs or work. They should not, as so often happens now, supplant them.
3. Wherever possible, residential services should be delivered to mentally handicapped people in their own home - whether this is their parental home, a group home, a staffed home, or an independent or shared flat. Mentally handicapped people should not be moved to alternative settings unless they have deliberately chosen this or the special help they need cannot be provided where they already live. In our residential service, it is staff, not clients, who are prepared to move flexibly to meet changing needs.
4. There must be a constant effort to provide the least restrictive possible residential setting for each client, recognising that every individual is capable of growing in independence and ability to exercise choice.
5. Services should be flexible. The convenience of using property which is already owned or leased should not override the needs of the individual.
6. The key investment of the service is not in buildings but in its staff and the way they work.
7. Wherever possible, the client should use services which are available to the rest of the community, rather than specialist services for mentally handicapped people.

Components of a comprehensive community service

This section gives a brief description of the component parts of a comprehensive residential service, in the context of a broader network of services to mentally handicapped people. It is a guide rather than a comprehensive list, and planners will certainly want to add their own components.

A range of places for people to live in

A comprehensive, community-based residential service should provide a range of places for people to live in. ENCOR uses the term ALU (alternative living unit). To British readers, this may sound like unnecessary jargon. It does, however, have the advantage of stressing the alternatives which are offered. We have settled for the word 'home' because, as we have said earlier, the concept and connotations of 'home' are of such fundamental importance to us all. But we hope readers will remember that by 'home' we do not mean exclusively either provision under the National Assistance Act 1948, nor a parental home, but simply the place where we live and which we call our own, chosen among a range of alternatives.

So, people who are mentally handicapped should be offered a real choice among the different sorts of home-life that would be recognised as such in the community. Often the choice would be provided within the community in which parents or family also live. Sometimes, it would be provided in a wider community, offering people the choice of living away from their family.

Ideally, each community or 'catchment area' should include these choices of home:

- a) the parental home
Support would be provided to clients and their families. This could be in the form of direct care - home help, companion or nurse coming to work in the home. Or it could be indirect - counselling, advice or training from psychologist, teacher or social worker.
- b) another family home
Here, families would be recruited to provide a home and training for clients, in a foster home for children, supported lodgings for adults. These families would be offered the same range of support as parents and relatives who have a handicapped person living with them.
- c) a house with live-in staff
The live-in staff could be full-time or part-time, and would have the support of non-resident staff as well as the range of indirect support offered in other homes. The level of staffing would be determined by the specific needs of the handicapped people living in the home.
- d) a house without live-in staff
Here full-time or part-time staff would provide direct support, if necessary, and indirect support would be available as it would to other homes. Again, the amount of support would be determined by the specific and individual needs of the handicapped people living in the home. So it could vary from minimal weekly supervision to up to forty hours a week. Some clients with very considerable needs for support can be served best by staff who do not live in. But a lot of thought must be given to continuity when many different staff are supporting one client.

An integrated system

All homes should be integrated into a system which ensures:

a) **mobility**

Clients and staff must be able to move within the system so that clients' needs are always being met in the best possible way. In a service based on the principle that, whenever possible, clients should be served in their own home - whether this is a family home, or a joint or independent living arrangement - staff will need to be prepared to move far more than often happens at the moment. As clients become more independent, staff may, in future, gradually be withdrawn from their home; it should not be necessary for clients themselves to move on to find the new level of support they need. Staff should also be able to provide direct or indirect care and support in more than one place; a live-in member of staff in one home may also provide part-time support to a neighbouring home, or staff who do not live in may share their time between several homes.

b) **different functions for different homes**

Most homes will be just that for the clients who live in them. This is in itself a specialised function. Other specialised functions will be needed too. Sometimes these will best be met in specialised homes, although non-specialised homes will also be able to take on some of them. These specialised functions include: supporting a cluster of homes (see diagram on page 20), and providing a short-term care service for: specific planned programmes of work with clients which cannot be done in their normal home; planned 'respite' for clients; planned 'respite' for families and substitute families; crisis support as needed for clients; crisis support as needed for families and substitute families.

c) **support for each cluster of homes**

Very small homes of the sort that we envisage need a range of supports which are readily and locally available. One way to ensure this is for one of the homes - usually slightly larger than the others - to provide 'core' services for the cluster. The core services include: I

Management: local residential managers, who provide support and supervision for the homes in the clusters are based at the core home.

Intake: some new clients coming into the local service go first to the core home for any assessment and training they may need.

Training: the core home staff offer basic training programmes to new clients and new staff as well.

Respite, relief and crisis support: the core home provides a reservoir of relief staff to homes in the cluster, as well as short-term care services for clients who need these.

A focal point for local services: core homes may come to provide a variety of other functions. They may be a central point of referral and contact for staff and clients; they may offer a central resource of staff and managerial expertise, as well as of psychological support; they may become the centre of a network of leisure time activities. Each local area will decide for itself how far the core home should take on any or all of these functions.

In every case, though, it should be remembered that the core home is home for the people who live in it. So it is preferable, for instance, to separate the 'office' functions of management and staff-support from the home life which is essential.

Integration with non-residential services

No residential service can stand alone. It must be closely integrated with other day-to-day services and with those which provide occasional but still essential help.

Examples of the first kind of service are:

- education for pre-school and school-age children and further education for adults;
- day, occupational and recreational services - like clubs, churches;

- work training, placement and supporting services;
- social security and other income maintenance programmes.

Examples of the second kind of service are:

- local GPs and hospital services;
- specialist diagnostic and assessment services;
- social work services;
- legal and welfare rights services and advocacy.

The 'core and cluster' principle

Short description: a spider diagram showing the types of homes that may make up a cluster of homes.

Long description:

The central box in the spider diagram contains the text: core home: 4-6 people plus resident staff, or living nearby.

There are 6 boxes surrounding this central box. These contain the following text:

1. Four-person group home with minimum support
2. Foster home caring for one person
3. Two-person home with care staff
4. Handicapped person living in own home with parents, but with support from core home
5. Two-person home with care staff living in and part-time help
6. Two to three person group home with medium support (20 hours per week)

Planning the service

The planners' objective should be to prepare the framework of services and to establish and sustain the right of mentally handicapped people to live in their community and lead as normal a life as they can. The framework must be soundly based and sensitive to the individual needs of its clients. It must offer the fewest restrictions and the largest number of options possible. It must be flexible enough to change in response to changing needs and social and economic circumstances. So planning does not simply mean a gathering of statistics on the supply of and demand for services. It involves a perception of how needs are changing and so of how different priorities arise at different times.

This means that planning cannot be seen as a once-for-all exercise. It is a continuous task, which involves gathering information, evaluating it, preparing short, medium and long-term plans, putting these into action and modifying them as necessary, and then gathering more information from evaluation of services on which to start planning again.

It also means that planning is too important to be left to "the planners". Everyone concerned with some part of the residential service must be involved – the clients, their families, and representatives of professional staff and statutory agencies, both administrators and practitioners.

There are three main types of planning to be done: planning the principles and policies of the service, operational planning and forward planning. We look at what each of these involves, in turn.

Planning principles and policies

An initial steering group will be needed to make explicit the philosophy, principles and broad objectives of the service. This job may be taken on by a District Planning Team or a Joint Care Planning Team sub-committee. In many cases, a completely separate group from these will be needed. The form the group takes will clearly depend on local circumstances. But three points are clear. First, local people must have a commitment to the new service, and this means involving them in its planning from the start. Second, the team, while being as small as possible, should also be representative of all the people and agencies involved in any future service, and include people who are currently working with mentally handicapped people, as well as administrators and managers. Third, the team must have the authority to ensure that action is taken on its proposals - which in turn depends on the close involvement of current service agencies. The present planning mechanisms, whether the strategic planning at regional level in the NHS, the planning arrangements of social services departments or the joint planning teams, often fail to meet these three conditions. So each locality will need to see how they can best be met in future.

The tasks of the team

1. Defining the philosophy of the residential service
This will lead to a definition of the objectives and goals of the service.
2. Defining the principles of the service
This will include defining the people who are to be served, which in turn means defining the service's catchment area and identifying the handicapped people within it. In a community-based service, people are said to come from the catchment area when: they already live in the area (either at home or in a hospital); OR their most involved next of kin live in the area; OR they are admitted to their present place of residence from an address in the area; OR they wish to live in the area for sound

practical or emotional reasons.

People in any of these categories are the responsibility of the area services and this responsibility should never be denied unless there is a firm guarantee that another area is taking responsibility, for instance, for people who have lived outside the catchment area and do not wish to return to it. In deciding which area is responsible, the wishes of the client and his or her family must always be taken into account.

The residential service will form part of a comprehensive overall service to all mentally handicapped people and their families in the area. So they should all be identified and known in advance to the planners of the service as potential users of it. It is relatively easy to identify people with severe mental handicaps, more difficult to identify those with mild mental handicaps whose use of the service will depend on local conditions and other variable factors. For planning purposes, the most satisfactory definition of mentally handicapped people is probably 'all those at present receiving services or on the records of service agencies because of a label or diagnosis of actual or suspected mental handicap'. Planners will be able to draw on the records and information of health, educational and social services and of voluntary organisations and residential homes to establish at least an approximate list of people in the area; they should also circulate all mental handicap hospitals in the United Kingdom to trace those who have moved out of the area and may wish to return to it, although there may be ways in which this task could be undertaken centrally. They may wish to mount a more detailed survey of numbers of potential clients and their abilities. But it should be clear that this is not a pre-condition to planning and launching a flexible service.

Advice on identifying mentally handicapped people in a given area and on using information about their needs to plan a service is available from: Dr. A. Kushlick, Health Care Evaluation Research Team, Dawn House, Sleepers Hill, Winchester, Hampshire; and from Development Team in Mental Handicap, Alexander Fleming House, Elephant & Castle, London SE1 6BY.23

3. Analysing on the basis of information about potential clients, the services that are likely to be needed.
4. Specifying the principle components of those services, including approximate staffing needs.
5. Establishing a management structure and outlines of job descriptions.
6. Establishing monitoring and evaluation procedures for all levels of the service.
7. Costing the service.
8. Obtaining agreement for the service and finance.
9. Ensuring that there is a management group, team or committee set up and working to implement the plans and maintain forward planning.

If little work of this kind has been done previously, these tasks should take between twelve and eighteen months.

Operational planning

This begins once the person or people are appointed to run the service. It is very important that the appointment of the service co-ordinators and other key professional workers is made a year or eighteen months before the service is expected to be fully operational. Part of their job will be to involve consumer representatives and other agencies in their tasks.

The tasks of operational planners

1. Ensuring that identification and referral systems for clients are working.
2. Assessing for named individuals what they will need in the way of services.
3. Defining in detail how the service will run.
This includes defining staff procedures, detailed policies and monitoring procedures. It includes drawing up special policies to encourage staff to collaborate with colleagues in other agencies. It includes defining the standards of the service, through written procedures, manuals, records and definitions of responsibility. We strongly recommend the work done in Wessex on planning residential units for mentally handicapped people.
4. Arranging for internal and outside training of staff.
5. Recruiting and training staff.
6. Beginning to draw up detailed individual programme plans for clients and to allocate services to them.

Forward planning

The future shape of the service will be affected by changes in demand for, or use of, services; changes in the incidence or prevalence of mental handicap; changes in the size and nature of the local population. It is the job of the forward planning team to ensure that these changes can be taken into account as the service develops.

Forward planning includes two essential approaches. It will be sensitive to requests for services at local levels - 'from below'. It will also take into account policies which come from different authorities and agencies as well as research literature - 'from above'.

The tasks of forward planners

1. Reviewing referral and identification procedures.
2. Collecting data from Individual Programme Plans on what services are needed but not yet provided, and using this to create new services.
3. Evaluating, at least once a year, the achievement of the service in the light of its specific stated objectives and examining the need for possible modifications or developments of these objectives.
4. Reviewing services in the light of monitoring of performance.
5. Re-allocating resources and obtaining additional ones to meet changing needs.

Service costing

Clearly the costing of new elements of service provision should be an integral part of planning processes. It is likely too that some effort to estimate future costings and make comparisons with existing and alternative forms of residential provision will be an important aspect of informed debate about the choice of new services. We know that some advocates of 'community care' have suggested that this is likely to be very much cheaper than care in a mental handicap hospital, while other people have argued the reverse. We accept the importance of cost comparisons but are wary of the crudeness which sometimes enters these debates. It is important that in making comparisons, we itemise and rate similar elements of a service. It is necessary to demonstrate that our comparisons relate to similar client populations. It is essential that we seek to compare not only costs but also the effectiveness of different kinds of service. Ultimately, we should also be concerned with costs and benefits to individuals and families, as well as that component of costs which is reflected in public expenditure.

With these points in mind we have not yet been able satisfactorily to undertake the work necessary to present valid comparative costs of old and new service provision. Our best bet is that both the costs and effectiveness of the residential services we have described will be higher than current average costs of residential care within hospitals. At the same time, such evidence as we have suggests that a good quality service can be provided in the community for no more than the costs of a well-staffed institutional option. This then is one area of exploration which we intend to pursue as a priority in future work and on which we would welcome assistance.

Individual programme plans

See the *Report of the Committee of Enquiry into Mental Handicap Nursing and Care* (Jay Report), Chapter 3 for a discussion of 'life plans'.

The Individual Programme Plan (IPP) has a vital place in a comprehensive community-based system of services. It is the basis of planning for individual clients, and ensures that those who come into contact with them regularly are together seeking the best possible services for them. It also ensures a consistency of approach: because specific objectives are set and ways of attaining these are agreed among all those who work regularly with an individual, the chances of different approaches being taken along the way are lessened. IPPs encourage the participation of clients and their families, no less than professionals, in both decision-making and the achievement of objectives. And finally, by pointing up the gap between what individuals need and what is currently available, IPPs yield invaluable information for the planning of service developments.

The IPP is essentially a written programme of intervention and action which is developed by the people who are regularly involved with an individual client. It defines a continuum of development and, after an initial assessment which tries to determine the degree of the client's developmental deficits, outlines progressive steps which the client can take in each area of development and the supports which will be needed. The overall aim is to enable the client to keep moving towards more independent functioning; IPPs are reviewed regularly, at least once a year.

The composition of the IPP team will change as the individual reaches different stages in his or her development. But typically this team will include

- professional workers: for example, speech therapist, physiotherapist, psychologist, psychiatrist and social worker
- representatives of services which the client uses regularly: for example, residential care staff, staff from school or place of work
- the client himself or herself
- the client's parents or legal guardian, who participate as equal members of the team.

The team will want to look at areas which help determine how independent the client is of specialised services. These include the following:

- cognitive skills: including concept formation, memory, concepts of money and time, and basic academic skills
- communication skills: speech and language
- daily living skills: self care and management, health care, preparation of food and home maintenance
- socialisation: interpersonal relationships, use of leisure time, adaptive behaviour
- motor skills: fine and gross
- skills related to work: work skills and habits, coping with pressure, following directions, persistence
- skills related to community life: using the telephone and public transport, understanding of community facilities, ability to make purchases and to use services
- recreation: use of leisure time, understanding of the way leisure facilities are used, choosing between them, making social acquaintances, finding a balance between individual and group activities
- health needs: regular preventive and remedial health care.

When the IPP team members meet, each one should identify the client's need from their own particular point of view. Often people from other disciplines will be able to help define these needs more precisely. The team's conclusions and decisions should be recorded, possibly on a form which includes a statement of long and short-term goals for the client, some indication of the methods, materials and rewards which may be used to meet these goals, and a clear statement of who is responsible for meeting each objective and of how and how often progress towards these is to be measured and the objectives themselves re-assessed. The objectives should be written in a language that everyone can understand: they should have to do with specific behaviours which the whole team agrees should be achieved. The goals should be as specific as possible, too; they should be measurable and a time limit should be set for achieving each of them. When a client has a number of needs, these should be set in order of priority.

Very often, of course, an identification of the client's needs will show up the gaps in what is available to help him or her meet them. That does not mean that the needs should then be tailored to existing services. Individual programme planning must clearly separate needs and possible action. A child with cerebral palsy living in hospital, for instance, might be agreed to need a substitute home and special schooling as well. The 'best' substitute home might be a foster home; the only practical solution might be a place in a residential special school. In a situation like this, it will be important for the IPP team to record clearly and separately what the child needs and what was actually possible. It is then that planners and managers should use written IPPs to find out the extent of un-met needs and work out ways of meeting them. In this case, for instance, they might think of developing a programme for fostering 'hard to place' children or local special schooling for children with specific sensory or physical handicaps. The IPP is not just the essential basis of help to individuals. It is also a valuable tool for making developing services sensitive to their real, as opposed to imagined, needs.

Guidelines on writing individual programme plans are available from:
NIMROD, Mental Handicap in Wales - Applied Research Unit, Ely Hospital Cowbridge Road,
Cardiff CF5 5XE

Housing

Each and every individual, no matter how handicapped, no matter how dependent, needs a house to live in. We all need four walls and a roof which enclose a private homely space in which we can live and do as we please and which we can stamp with our own personality through furnishings and decorations. So one component of a residential service for mentally handicapped people is quite simple: a range of houses for them to live in, which is as near the range of housing offered to non-handicapped people as possible.

In the past, a major obstacle to the provision of this range of housing for mentally handicapped people has been the confusion between their common need for a house and their varying needs for 'care' and other services. So it has been assumed that they cannot live in ordinary housing and that purpose-building of 'special' places must be the rule. So too, local authorities have tended not to meet housing needs for this group of people as they would for any other. Housing for mentally handicapped people has been seen as a health or social service rather than part of the normal housing service provided for a large section of the rest of the population. Local authorities have not used their considerable powers to meet the housing needs of mentally handicapped people.

In this section, we look at those powers, for we believe that the time has come for local authorities to start using them for mentally handicapped people no less than for the rest of the population. But first we look at what mentally handicapped people may need by way of housing and at what is currently available. Existing housing has so many advantages and there is such a variety of it, that purpose-building may very seldom be needed. When purpose-building is chosen, it should be because the area has a shortage of houses. A comprehensive, community-based residential service does not use 'special' hostels and the like, for its message is that mentally handicapped people have the right to share in normal patterns of community life.

What sort of housing?

The first rule is that it should not stand out among other local housing by having special distinguishing or stigmatising features like signs, additional parking space, lighting, nameboard or external escape staircase. The house will be of a size and scale that is recognisably within the normal range. It will have the facilities and homeliness that an ordinary working family would ask for itself. It will take individual needs for privacy into account and provide single and double rooms.

The second rule is that the housing will be within easy reach of community facilities and employment. Most mentally handicapped people will not have a driving licence and even fewer will have the resources to get themselves a car. Their only form of independent transport will be bicycles and wheelchairs. So their houses should be near shops, schools, factories, libraries, pubs and other community leisure places. Clearly the ideal site will not always be found, and the priority needs of the individual may not always include relationships with the local community. But a shopping centre within walking distance or a short bus ride is one rule of thumb which should not be compromised.

Service providers will have to consider whether to lease or purchase housing. The criteria for purchase should be the same as they are for people who are likely to be competing for the property. It must be mortgageable, it must meet the needs of the people who are to live in it either completely or with only modest adaptation, it must be a sound 'household' investment and have a reasonable life expectancy. If the house

is owned by the local authority or leased from a Town Development Corporation or other agency, then it should be chosen for the same reason that the neighbours chose theirs: because of its suitable size, location, amenities, condition and the cost of rent and heating.

Providers will have to check with the local authority what constraints there might be on occupancy. If the house is to be categorised as multiple-occupancy, there will be a delay while change-of-use procedures are worked through. This categorisation may bring more serious problems, because if the local authority insists that the house is defined as Purpose Group Two under the building regulations (Part E), it will be classed as institutional'. This will bring a whole series of means of escape and fire- resistance conditions which are both intrusive and expensive. Exactly what constitutes multiple-occupancy is a matter of the planning officer's interpretation; the normal rule is that an assembly of people sharing common facilities, rather than living like a normal family, will be classed in this way. But the providers of the house are able to appeal against classification of it as multiple-occupancy, and we believe that they should. If people can live satisfactorily in small houses with support services, then their needs for sophisticated fire regulations are the same as those of the rest of the population.

Providers will also have to work out what 'special' elements may be needed inside the house to meet the needs of the people who live there. Some of them, for instance, may have physical disabilities. It may be possible to get financial help for adaptations in the form of an improvement grant, under the discretionary powers given to district councils by the Housing Act, 1974. Whatever adaptations need to be made, the aim should be that the house remains an ordinary house, similar to those lived in by people who are not handicapped.

Mentally handicapped people, like anyone else, grow through learning to cope with risk in everyday life and their right to take risks has been increasingly recognised in recent years. The selection of housing and where it is situated will determine many of the risks that its occupants will run. The people who select housing for individuals will know, from their Individual Programme Plans, what the range of risks should be. This will help them choose both the location of the house and what modifications, if any, should be made beyond those which ensure building safety for the general population. In some circumstances and for some people, for instance, it may be necessary to exclude gas heating and cooking fuel; to ensure that windows either open up and down or slide; or to provide door locks which have a thumb-turn on the inside rather than keys.

What housing is available?

Public sector housing

This provides a huge potential for mentally handicapped people, including those who are very dependent indeed. Most housing, particularly that built recently, has high standards of space and amenity. An increasing proportion is built to mobility standards which make it convenient for mentally handicapped people who have a physical disability to live in. Housing authorities can be asked to adapt ordinary housing to provide the extra space which may be needed when there are many visiting helpers, or to provide a downstairs bedroom and lavatory. The range of housing provided is widening, and single persons accommodation or two-person flats may suit some mentally handicapped people who do not need a great deal of support.

Many housing authorities already allow people in hospital to register on their waiting list and they may give points for medical priority. If they use their nomination rights flexibly, they can provide housing opportunities for many people now in hospital or hostels. There is scope for far greater co-operation between housing, social services and health authorities, and voluntary agencies, to provide housing and the support that is needed. For instance, social

services, health authorities and individual hospitals can all hold nomination rights to selected housing which enable them to house their clients outside the waiting list for housing.

Housing associations

These have a major role to play in housing mentally handicapped people. There is a growing interest among them in providing housing for people with special needs and funds are now available for housing projects for people who need a substantial amount of care.(' So housing associations can be encouraged to work together with statutory and voluntary agencies which understand the needs of mentally handicapped people. Several schemes already exist where the association provides the building and others provide the specialist input and support.

Private sector housing

Statutory or voluntary agencies may prefer to buy housing on the open market if they feel it will provide better accommodation for their clients. This has its advantages: the choice of properties will be wider, and very specific requirements like being near the family - can be met. It also enables the integration of mentally handicapped people into ordinary community settings.

Fostering and lodgings

Fostering has long been an accepted way of offering a home to live in to children who are unable to stay with their own families and although few authorities as yet have special fostering programmes for mentally handicapped children, many include them in their general fostering schemes or in schemes for 'hard-to-place children. We believe that this resource could be far more widely used. Taking lodgings in someone else's house is a time honoured way of finding housing for single people and many more mentally handicapped people could tap this source of housing than now get the chance. We suggest that in each area, a particular agency or voluntary group is responsible for co-ordinating a lodgings scheme and keeping a list of landladies, matching landladies to clients and providing the necessary support.

Short life housing

Short life property is a valuable resource for local authorities in their battle against homelessness and for people who want to try out new ways of living together. It is cheap to the public and to its occupants and often has the additional advantage of being in busy urban areas. Housing associations can claim grants to help them use this sort of property. Mentally handicapped people who are looking for a more or less temporary home may wish to take advantage of this. At the same time, a short life property may turn out to have a fair degree of longevity.

Legislation: powers and duties

Three pieces of legislation cover the powers and duties of local authorities to provide accommodation for mentally handicapped people: *the National Assistance Act, 1948*; the *Mental Health Act, 1959*; and the *National Health Services Act, 1977* (Section 21). It is because the responsibility for providing accommodation under these Acts rests with social services and health authorities rather than with housing departments that we have run into the confusion between the need for housing and the need for care, and that the potential role of housing authorities has been neglected.

The Chronically Sick and Disabled Persons Act, 1970, requires local housing authorities to consider the special needs of handicapped people when they provide housing. The Act does

not exclude mentally handicapped people, but has usually been interpreted to cover only physically disabled people. It is from this that we have seen the development of wheelchair, mobility and other specially adapted housing.

There is, however, nothing at all in current housing legislation to stop housing authorities from providing the full range of housing that mentally handicapped people may need. Housing authorities already have the power to provide shared and single tenancies, bed-sitters, group homes, sheltered housing with a warden, lodgings and hostels.

The *Housing Act, 1957* sets out the main housing functions of local authorities and their duties to consider the needs of their area and to provide accordingly. The Act also gives them the power to acquire property and land.

The *Housing Act, 1969* gives the local authority the duty to carry out an inspection of its area 'from time to time¹ in order to see how it should be meeting its obligations under the 1957 Act.

The *Housing Act, 1974* extended the 1957 Act to include hostel accommodation which provides either board or facilities for the preparation of food. The Act prescribes the role of the Housing Corporation and provides for the registration of and granting of financial help to housing associations. It also gives housing authorities power to make improvement grants to handicapped people to adapt their homes. *Circular 13/75 (Housing Act, 1974: Renewal Strategies)* gave local authorities the power to meet the special needs of homeless, elderly and disabled people within their overall housing strategy.

The Housing (Homeless Persons) Act, 1977 gives housing authorities a firm responsibility for meeting the needs of homeless people, a group it defined for the first time. Mentally ill and handicapped people are among the priority groups entitled to housing obtained by the local authority if they are homeless or threatened with homelessness. What is not clear is whether people who remain in hospital simply because they have nowhere else to go can be considered as 'homeless' under the Act. We believe that to all intents and purposes, homeless is what they are.

Advice to the voluntary housing movement has been more specifically directed to the needs of special groups, including mentally handicapped people. The relevant circulars are:

- DoE Circular 170/74 (Welsh Office Circular 274/74): Housing Act, 1974. Housing Corporation and Housing Associations
- DoE Circular 103/77 (Welsh Office Circular 162/77): Housing Act, 1974. Part III calculation and payment of housing association grant
- DoE Circular 64/78: Housing Act, 1974. Housing Association Grant: Administration allowances
- Housing Corporation Circular 1/77: Joint Funding Arrangements for Caring Hostel Projects

Housing authorities and housing associations, in short, have all the powers they need to play their part in the creation of a comprehensive, community-based residential service for mentally handicapped people. Their task now, in co-operation with the other relevant agencies and organisations, is to use those powers to the full.

Staffing the service

It is easier to talk about the work done by residential staff in terms that are general, descriptive and evocative than in terms that are scientific, precise and formal. In this section, we have tried to use terms which are as precise as possible and we hope that readers will understand why we are trying to tease out exactly what it is that staff do in this way. We use words like tasks, skills, performances and account-ability. Others might choose to use words like being with, loving, empathising with and respecting. These are all things which staff should be and do and our own use of terminology should not in any way belie them.

Residential work is done at three main levels. At the first level, direct care staff are interacting directly with clients. Almost all their working day is spent in close company with them and many of the clients' most significant daily experiences are shared with these staff. At the next level, senior care staff also spend a good part of their time in direct care of clients. But they also spend a good deal of time in supervising and co-ordinating the work of direct care staff, making day-to-day decisions about their work and recording information about staff and clients. They are concerned with the admission, discharge and moving of clients, with organising the main activities and staff deployment within individual houses and with informing clients' relatives and staff about programmes.

At a third level, managers of the service are hardly involved in direct care at all, except perhaps where care staff are having particular difficulties. Their main tasks have to do with supervising, co-ordinating and supporting the work of staff at these other levels. The managers appoint these staff, deploy them and plan their work; they supervise and monitor and provide information, advice and support. They are also involved in operational planning, within a framework drawn by more senior managers and strategic planners; they plan the day-to-day and week-to-week routines of the service and are involved in longer term planning as well. (See analysis of levels of work in the Jay Report pp. 108-109 (4) and *Wessex Health Care Evaluation Research Team Report - evidence to the Committee of Enquiry in Mental Handicap Nursing and Care*)

The tasks of direct care staff

Clearly these tasks will vary considerably over time, as the needs and dependence of clients, in different areas of their lives, keep changing. Whatever the specific tasks required, though, they will fall into one of two categories: 'teaching' and 'doing'. The first involves identifying the areas where clients lack the skills they need to be independent in everyday life and helping them to acquire these skills. These tasks include problem-solving - identifying problems, setting priorities, planning and implementing solutions - preparing materials and settings, teaching particular activities and shaping behaviour. The second kind of task involves doing things for clients which they need to be able to do but cannot yet do for themselves. With very dependent clients, staff will spend much of their time in these tasks. But they will always need to put as much emphasis as possible on teaching as well.

The essential of the direct care staff job overall is that it involves both teaching and doing tasks. Very often at the moment, different kinds of staff are recruited for the two different sorts of task. There are 'domestic' staff, who are do-ers, and there are 'care' staff who combine some doing with some teaching. This division of roles is not a useful one in the residential service we are outlining and we would abolish the distinction between 'domestic' and 'care' staff. Many clients will need to be served by staff who are do-ers of routine daily living tasks for them, but who are also analysing their skill-deficits, and creating learning opportunities for them.

Both doing and teaching need to be done in the ordinary activities of everyday life - sleeping, washing, dressing, using the toilet, eating, going out and engaging in interesting and useful activities. These home-making tasks fall into clusters - self-care, daily living activities, recreation and leisure, and work and occupation. Staff are responsible for seeing that daily routines and programmes cover each of these clusters. It is also important that their caring role is seen as going well beyond the confines of the home. A home-life for any of us includes regular contact with a number of people who live outside its four walls - neighbours, family and relatives, friends, tradespeople and casual acquaintances. Staff will have to ensure these contacts are made and maintained and teach the clients to make and maintain them for themselves. Finally, staff will have to work in unaccustomed settings. Many of them will not work in residential homes owned by an employing authority or agency. They will work instead in clients' homes - either parental homes or the homes of which the clients are principal tenants or users. In these settings, staff will need to learn to work very much as enablers, identifying the wishes of the clients as well as their needs and working towards fulfilling these wishes, rather than themselves identifying the needs and working on them.

The tasks of managers

1. Selection of staff and ensuring relevant training

Each of the tasks we have outlined for direct care staff demands specific skills of them. The skills are mainly very ordinary ones: because staff themselves live in society and do most of these activities for themselves every day, they have the skills already. But many of them need training which extends their skills, and most need training and support to bring out their latent ones. In addition, all staff need training in the techniques of identifying needs, deciding priorities, setting programmes and teaching skills to clients. Selection and training of staff - both initial and in-service - needs to meet the demand for these skills. In many cases the formal qualifications of staff and programmes of training currently provided for them are quite irrelevant to their needs. So planners and providers of services will need to take careful note of the skills needed and how to provide them, whatever the qualifications staff may hold when they join the service.

2. Deployment of staff

A client who is at first very dependent may, as he or she gains new skills, need less time and attention from staff. A client who is fairly independent may go through a crisis in which he or she needs considerable support for a time. So if the needs of clients are to be properly met, staff deployment may have to be very flexible. Staff may gradually be withdrawn from a home in which they have been working; they may be asked to work in another where there is a particular need for their skills. In most, though not all, situations, the response to the changing needs of clients will be not a move for them to another home, but a move for staff.

This approach, which we see as critical in the sort of residential service we are talking about, turns traditional responses to changing client needs on their head. Traditionally, staff become attached to working in particular buildings; clients are assumed not to develop this sort of attachment to their home. Often buildings and staff together are considered as a 'unit' which offers a specific service - 'special care', 'intensive therapy', 'pre-discharge rehabilitation' and so on. But, as we know, this 'specialised unit' strategy brings a good number of problems. The needs of staff may take precedence over those of clients and many kinds of rigid practice may creep in. Clients who are moved from unit to unit (from what, after all, is home to home) suffer unnecessary and often harmful disruptions to their homelife.

If this sort of disruption is to be avoided, it is staff rather than clients who should usually move as needs change. This demands management which encourages

adaptability among staff and is highly sensitive to how they should be deployed, as well as offering them a good deal of support.

3. Supporting staff

The greatest danger for any home for handicapped people, whether large or small, is isolation. Managers and senior care staff too have a particular responsibility to make sure that neither clients nor direct care staff become isolated. For staff, this entails ensuring regular contact with colleagues in other homes for handicapped and other people, the chance to meet colleagues and exchange ideas and mutual support at training activities, and regular contacts with friends and acquaintances who have nothing to do with their work at all.

So managers will need to keep residential staff informed about all local resources - including ordinary community facilities as well as sources of specialist help for themselves and their clients. They will need to ensure that meetings are held between their staff and these specialist helpers, and make sure that their staff visit other agencies and places where people live.

The managers will also visit the home regularly and often, and at unpredictable as well as predictable times. They will make sure that there are regular and frequent staff meetings and that these are satisfying rather than frustrating. These meetings will range from the daily house staff meeting to exchange information, to the weekly meetings of the staff of the cluster of homes which will be particularly geared to staff support, to the monthly meetings of all staff with the managers and other professional workers with a regular commitment to the homes. The managers will also ensure that they do not provide the only support for staff, that professional advisers are also directly accessible to them. Finally, the managers will ensure that the staff have accurate information about local and national plans and trends in mental handicap services and the opportunity to discuss the relevance of these to their own work and make suggestions.

4. Maintaining accountability

Managers of a residential service maintain accountability to clients, their relatives and the managers of the service as a whole in at least two ways. The first of these is internal, and involves 'positive monitoring'. The second is more external, and possibly involves people from outside the service altogether offering some independent checks on its quality. We look at these in some detail in the next section.

Monitoring and evaluation

Monitoring is the means that providers of a service and staff at all levels use to ensure that the service is remaining true to its original goals and is continuing to meet the needs of its clients. It is an important way of supporting staff, and making sure that their work continues to be of a high standard. Evaluation incorporates these elements, but also reviews the way in which the service is delivered and compares this with alternative models of service. It gives advice to service planners about the nature and calibre of the service itself. Monitoring and evaluation are both important parts of a residential service which is truly responsive to clients' needs and continues to be so.

There has been little use of either monitoring or evaluation in the past. The assumption has been that the best way to establish high quality services is to recruit staff whose own quality is high and who are well motivated. But experience suggests that this is not enough. Over time, even the most conscientious of staff can let their standards drop; as the original staff leave and are replaced, there can also be a gradual drift in the quality of services. So monitoring and evaluation are essential safeguards of the service and for the staff themselves.

Some monitoring will be internal - information about the quality of the service will be collected by its staff as part of their managerial responsibilities. It may also be important to establish an external monitoring system, in which people with no vested interest in the day-to-day running of the service collect information about it. In the health service, the community health council could be involved: alternatively, this could be the task of a project management group or an organisation which represents the consumers of the service. For both internal and external monitoring there should be clearly specified procedures for the collection of information, so that everyone concerned is fully aware of his or her responsibilities.

Stages in the process

There are three main stages in the monitoring and evaluation process:

1. Making explicit the goals of the service and ways of achieving them.
There are now a number of documents which set out goals for units serving mentally handicapped people. * They vary considerably in scope and detail. They have to do mostly with the impact of the service on its consumers, covering the extent to which they are living in a 'normalised' way, learning new skills, are healthy and satisfied with the service. Each of these goals needs to be stated much more specifically before going on to consider the different methods for meeting them.

These methods may include the provision of specific facilities, standards for buildings, space for personal possessions and privacy - to take just some examples. It is often much easier to specify these aspects of a service than its effects on its clients, and the people who are responsible for monitoring and evaluation procedures need to be careful that standards for the 'hardware' of the service do not take precedence over aspects which are more directly related to the clients. Standards of staff performance must also be specified. These may relate to the way in which staff interact with the handicapped people and to the provision of Individual Programme Plans and regular review of each client's progress.
2. Devising and using a means of collecting information about the extent to which: these goals are being met; the methods for achieving them are being used effectively; the service compares favourably with alternative services.

Most of the standard documents cited in the bibliography contain a checklist which is used as a basis for collecting information about the quality of service. The more specific the checklist, the easier it will be to collect objective information. This needs to be done as a matter of routine.

3. Devising and using a means of feeding back this information to all relevant staff, so that there can be improvements in both their performance and the service overall.

For monitoring and evaluation to be effective, it is important that staff at both direct care and management levels get information about what has been discovered. ^ They should get it as quickly as possible and it should be constructive, giving recognition to staff when their work meets the declared standards and constructive suggestions for improvement when it falls short of these. It is often easier to highlight the negative aspects of a service, but that is not the way in which a high quality service is maintained in the long run.

Positive monitoring

This is one method of making sure that the feedback to staff on their performance is helpful to them and so to the clients they serve and the service itself. Positive monitoring means, quite simply, telling staff when they are doing something correctly, and giving constructive comments when improvements are needed.* It ensures that monitoring becomes helpful to staff and so welcomed by them.

Positive monitoring shows that an exercise of this sort need not be time- consuming: the checklist it offers for each area of responsibility usually takes only a few minutes to complete. By using written comments on the checklist, it ensures that staff have every chance to study what the monitor has found and discuss the findings openly. It does not disrupt what is normally going on for either staff or clients. It ensures that the clients are being treated fairly and considerately. It is a way of letting staff know when they are doing a good job, and so improving morale, while offering calm and constructive way of dealing with potential problems so that they can do their job better.

Local strategies for innovation

We have argued in this paper that the development of better services for mentally handicapped people demands careful consideration of the kinds of provision we are aiming for, rational examination of what changes are feasible, and detailed analysis of each new aspect of the service. But real innovation depends on sustained local action. At the end of the day, services will only improve through the initiative of local people and their success in mobilising support.

So we want to learn more about the local strategies needed to create new services, and about what sort of help local people will need. There is as yet no carefully documented example of British efforts to create the kind of service we want to see. Clearly approaches will vary with local circumstances; indeed, real change depends on local people accepting responsibility for making and evaluating their own innovations. Clearly too, there will be considerable problems to be overcome; our own experiences highlight these just as much as they do the successes. What this says to us is that we should try hard to learn from each other's experiences to establish the best ways forward. So in this section, we try to highlight some key questions for local people who want to see change, and to offer some tentative responses to them from our own experiences.

To begin at the beginning: before setting out on what is likely to be a long and thorny path, individuals and groups will need to review carefully the strengths and weaknesses of existing mental handicap services in their area, and think through the philosophy which should underpin innovation. If the ideas in this paper seem likely to have a strong appeal, then nine main questions will need to be tackled if ideas and aspirations are to be translated into real services.

1. **Who are the other key local people we should try to interest in our ideas? What kind of coalition do we need to mobilise to ensure that these ideas are given proper attention when policy is made?**

It seems clear to us that alternative residential services are more likely to be developed when there is both close collaboration between statutory services - particularly health and social services, education and housing - and keen interest from voluntary and parent groups. It also seems likely that real innovation depends on mutually supportive interest in services to mentally handicapped people among providers and planners, officers and members. It is when this interest exists that a network of key local people can be created to give weight to the new proposals and sustain ideas through the processes of accommodation and attrition which commonly seem to arise as plans are developed and implemented.

So our experience suggests that real progress depends on their being a small of influential local people, including well placed practitioners and articulate consumers, who are able to support each other through periods of delay and opposition and at the same time to work with a wider network of sympathetic office-holders. This network of support could be sought in the local authority - from officers of social services, education and housing departments and members of the relevant committees, including Policy and Resources; in the health service, from members of the District39 Management Team, influential professionals like the local consultant in mental handicap and senior psychologists, members of the area health authority and the community health council; and among relevant local bodies, like Mencap and sometimes Rotary. A few forward-looking and well-informed members of the local authority, area health authority and joint consultative committee can be particularly valuable in leading rather than following their officers and keeping issues about mental handicap on the agendas of agencies which can - barring scandals - so easily

have 'bigger' problems to tackle. For some developments, interest from Ministers can also be very significant.

2. Which are the most relevant formal planning and management forums in which new service developments will, in the end, need to find favour?

It seems to us that it is quite often difficult to identify who is making decisions about mental handicap services. Where the National Development Group's advice has been followed, a sub-group of the Joint Care Planning Team at area health authority/ local authority level should be giving specific attention to developing these services. Where this group does exist, it should be a critical forum for influencing the commitments made by different local agencies, through the allocation of joint finance and in other ways. But the NDG's advice is not always followed. And even where JCPTs are operating, they are often less than effective. A planning forum in itself will achieve little without innovative leadership and people who are willing and able to do the extensive preparatory work involved in drafting the detailed requirements for new services. It seems to us that the relatively small size of mental handicap services, the common lack of expertise on these services in the upper echelons of the agency hierarchies and the fragmentation of existing provision can all serve to undermine any efforts at radical innovation.

So what is needed is a coalition of influences which gives identity and political weight to the needs of mentally handicapped people and their families – in both the formal decision-making machinery and the more informal influencing of key figures, which may be even more important to what decisions are actually made. Strong support among the decision-makers in each agency - District Management Teams, for instance, and executive groups in social services departments - will also be important. So will an active District Planning Team for mental handicap services and possibly an officer group which is looking at the possibility of local experiments for perhaps 50,000 people and has a proper mandate from the agencies involved to do so. Finally, a 'shadow' planning group may be valuable, particularly if, like some mental handicap sub-groups of the community health council, it represents consumer interests and is able to stimulate and reinforce the efforts of officers.

3. How should we go about generating wider interest and support for this new pattern of services? How can clients, parents, front-line staff, senior professional and community interests be involved in creating, rather than just reacting to, new services?

Just being prepared to talk to anybody remotely concerned and to emphasise the fact that mentally handicapped people learn and change, that working with them is usually rewarding and not depressing, is always important. Welcoming any good new aspects of service available locally can lead to questions about past assumptions and the implicit culture of segregation and ignorance. It is important too to recognise that ordinary people can be both accepting and supportive of new services in their communities if they are approached in the right way and the new developments do not stand out from conventional ways of home-making. Discussion in the local press and occasional spots on local radio to talk about local hopes and ideas can both contribute to the momentum. They keep local people informed and create interest, and will also encourage local councillors, members of authorities and senior officers, to keep abreast of needs and possibilities in the field of mental handicap.

4. How can we persuade the main local decision-makers that this new kind of service is possible? How should we respond to managers who say it would not work, or would be too expensive? How should we answer 'experts' who claim it would not meet the true needs of mentally handicapped people?

We are aware of how all too easily local policy-makers can become preoccupied with the size of problems and gross statistics, or see provision almost entirely in terms of

long-term residential placements for people from a large population. There are advantages in keeping thinking very local and examining the variety of services needed for a small population. Where there are already elements of services, like an adult training centre, and where local agencies might be persuaded to consider further local developments in response to carefully identified needs, there will be a basis on which to build and test elements of our alternative residential service.

We have found it helpful to meet scepticism on costs by asking local authority or area health authority treasurers to carry out their own costing exercise. Preliminary work we know of suggests that services based on ordinary housing are comparable in cost to other well-staffed provision based on a more institutional model.

Our response to other kinds of scepticism is to insist on distinguishing myth from reality and compare the actual experience of mentally handicapped people in more traditional forms of care with their actual experience in the service we are suggesting. We would also stress the rights of mentally handicapped people as citizens and the contribution they can make to society, as against the wastefulness of much current provision.

5. Should we start by establishing one or two elements of a new service and building from there? Or will our best chance come by arguing from the outset for a comprehensive new service? Are there ways of combining the two approaches?

We tend to be in favour of starting small, to demonstrate the worth and acceptability of the new kinds of service we are proposing. But we also see value in more comprehensive attempts to establish and evaluate alternative residential services if many local conditions are already favourable or if a major change is needed anyway - for example, because a large hospital is to be closed. The choice may, however, be a false one. There may be a need both to plan comprehensively for new patterns of services and to implement these plans gradually as opportunities can be created.

6. How can we ensure successful transition from the old to the new pattern of services? How can we gain the commitment of staff?

The fragmentation of existing provision means that very few, if any, of the people involved in planning or delivering services feel themselves to be part of the total service. So new developments are very often seen as split off from and even antagonistic to what is happening now. This makes it difficult to gain the full support of staff working in the old service. It is important, then, to help staff feel involved in the total service, including its new aspects. Staff working in large hospitals, for instance, may need opportunities both to improve the services these offer as the number of residents falls, and to identify with the growth of community-based services to parts of existing catchment areas. We also think there is a need, at both operational and planning levels, to bring together within a common forum representatives of everyone who will be involved in developing new services. If attention can be focused on the shared task of improving services, there will be an opportunity to work through the anxieties and difficulties brought by any significant change.

7. What problems are likely to arise on the way to establishing the new service? How can these be overcome?

It is realistic to accept that there are considerable problems in introducing and sustaining any innovation. Many of the people who make decisions about mentally handicapped people have only very part-time involvement in services to them. In hierarchical agencies, it is still common for senior people to enforce approaches which have little to do with the special needs of these clients. At the same time, agencies and professional workers can easily throw up barriers to collaboration and pursue different goals for clients - sometimes without ever making these explicit.

Different priorities in different agencies and a tendency to timidity in the face of challenge bring their own problems.

Probably the best long-term investment in overcoming all these problems is in steady pressure to raise expectations and change attitudes about handicap in the local agencies. Here national policy guidance, like the National Development Group pamphlets, can be a helpful focus for discussion about the practical steps forward which will challenge conventional wisdom.

8. **How can we develop a new pattern of services which does more than transfer old patterns to new places?**

In any uncertain situation, it is always easier to fall back into well-tried and traditional methods than to sustain the struggle for genuine innovation. Relationships between parents and service providers, forms of staff training and supervision and the ways in which decisions are made may all act as blocks to establishing a genuinely new service. Even fairly simple changes, like abolishing the distinction between direct care and housekeeping, may involve major effort where wider assumptions about non-nursing duties run right against the philosophy and specific needs of the new service.

Innovation, of course, is rarely achieved once for all. We will have to work hard to sustain the gains and to build on these, for each of these should help to create an interlocking set of service elements which together will eventually add up to a resilient system. The efforts to sustain gains are likely to be reinforced where parents and others are regularly and continually involved in monitoring the new service.

9. **What kind of outside help do we need to develop a comprehensive community-based service?**

Here we particularly need and invite the views of the people who read this paper and share our aspirations. The answers will come from them.

Several members of the working group have found that their own visits to ENCOR and discussions with colleagues about it have given them increased confidence in their own efforts to develop alternative local residential services. A trip to the United States is not going to be offered to very many people. But the King's Fund Centre is developing a register of people who are doing work similar to that of ENCOR in the United Kingdom and who will welcome sympathetic and interested visitors.

The King's Fund Centre is also willing to convene a series of workshops on specific issues raised by this paper and by other local experience. We shall need to know from you what demand exists for these.

We also hope, through the contacts made by the working group and responses to this paper, to extend the supportive network of colleagues who are willing to offer each other advice and work through thorny problems together.

All these we see as steps towards establishing a new residential service for mentally handicapped people which is based in local initiatives. We hope this paper will give further impetus to these efforts and we are ourselves keen, with support from the King's Fund Centre, to share with others in taking this work forward. But in the end, a comprehensive locally-based residential service for mentally handicapped people will grow from the enthusiasm, initiatives and sheer doggedness of local people. That is the challenge to everyone who reads this paper. We believe that mentally handicapped people have the right to expect that it will be taken up.

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