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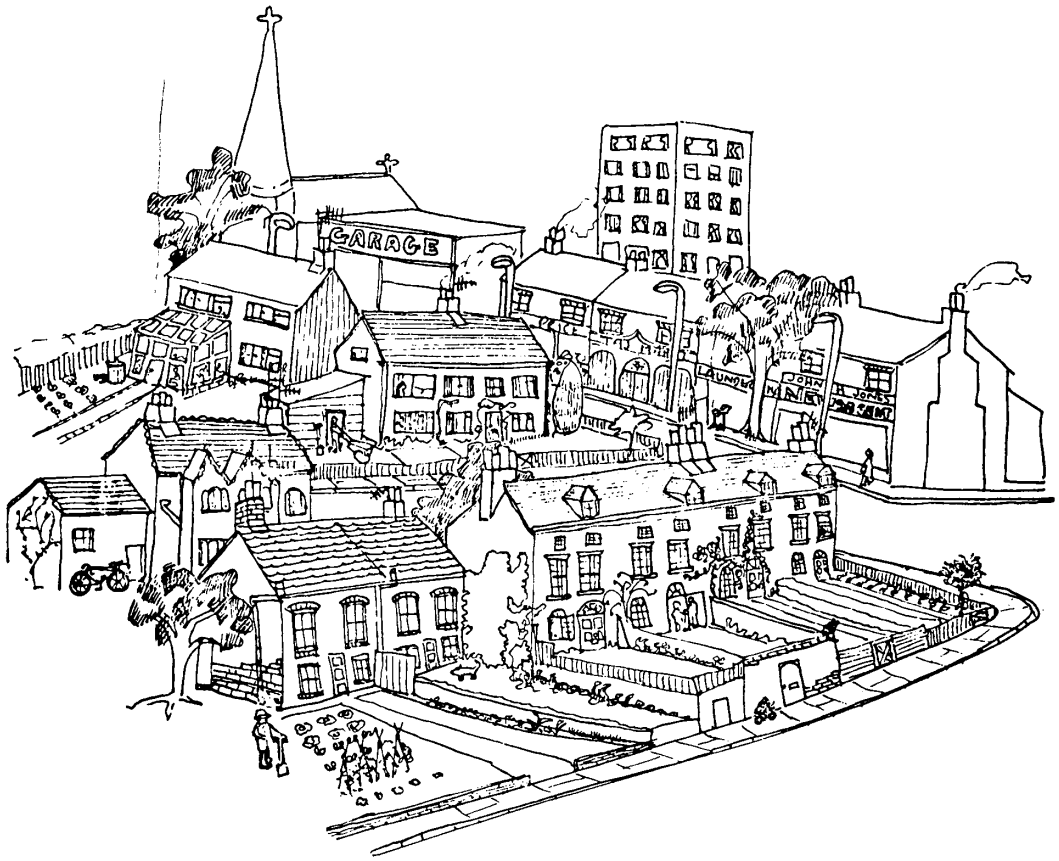
MENTALLY HANDICAPPED PEOPLE WITH SPECIAL NEEDS



MELINDA FIRTH & HUGH FIRTH

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MENTALLY HANDICAPPED PEOPLE WITH SPECIAL NEEDS

by Melinda Firth and Hugh Firth

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PREFACE

In 1978, the King's Fund Centre set up a working group to consider what is necessary to provide comprehensive locally based residential services for all mentally handicapped people. This working group (generally known as 'An Ordinary Life' working group) produced a project paper (King's Fund Project Paper No 24) in February 1980 entitled 'An Ordinary Life: comprehensive locally-based residential services for mentally handicapped people'.

In November 1981 the King's Fund held a one-day workshop entitled 'Mentally Handicapped People with Special Needs' as part of the 'Ordinary Life' initiative. The people who presented the material at the workshop were:

Hugh Firth,
Clinical Psychologist,
Prudhoe Hospital,
Prudhoe, Northumberland.

Jan Porterfield,
Research Worker,
Mental Handicap in Wales,
Applied Research Unit,
Cardiff.

Alan Tyne,
Research Worker,
Campaign for Mentally Handicapped People,
London.

Mary Myers,
Consultant in the Psychiatry of Mental Handicap,
Beechcroft, Oakwood,
Rotherham, South Yorks.

David Towell,
Assistant Director,
King's Fund Centre

Alison Wertheimer
Organiser,
Campaign for Mentally Handicapped People,
London

The workshop focussed on mentally handicapped people with special needs, including particularly those with additional physical handicaps, behavioural disturbances, and profoundly mentally handicapped people.

The ideas in this discussion paper are not a report of the workshop, but rather a synthesis of the ideas presented on the day, together with developments in the thinking of working group members.

INTRODUCTION

This discussion paper is about the provision of services for mentally handicapped people who, for one reason or another, have some special needs. This paper is about services for people who, as well as being mentally retarded, have some other reason for needing services.

These people may be blind or partially sighted, deaf or partially hearing, physically handicapped, epileptic, autistic, elderly, profoundly handicapped, or may show very disturbed behaviour at times.

However, one group of people whose needs we do not consider in this paper are those mentally retarded people whose behaviour has resulted in restrictions to their freedom imposed by the law.

For more than 20 years there has been a growing awareness of the rights and needs of mentally handicapped people to have access to the same facilities as other people. Those of us who aim to enable all mentally handicapped people to enjoy their rights have been aware for many years that physical and social segregation of mentally handicapped people is unacceptable. It is those people with special needs who have been most subject to such segregation.

Whilst, since the late 1950's there has been a great deal of interest in the concept of 'community care', the change in emphasis away from institutional care was originally heavily influenced by increasing knowledge of the disadvantages of institutional care rather than through recognition of the rights, and needs, of those mentally handicapped people who are cared for in institutions.

The value of caring for mentally handicapped people in small groups in the community has been recognised and research workers (Tizard 1964*) have shown that a homely environment can contribute far more to the development of mentally handicapped people than institutional care. One advantage of social integration of mentally handicapped people is that they develop skills more rapidly when they live with non-handicapped people than when living mainly or solely with other handicapped people.

If, therefore, there is genuine concern to provide 'community care', and this concern is backed up by research results confirming the advantages of such a model of care, why then are 2,000 mentally handicapped children and 50,000 mentally handicapped adults still being cared for in institutions?

Lack of resources is clearly a problem for all service providers. More important stumbling blocks in many cases are the written or unwritten pronciples of service provision which service providers adhere to. These principles can promote further categorisation of mentally handicapped people and the belief that some mentally handicapped people will always require hospital care - those severely, profoundly, or multiply handicapped people who are the focus of this discussion paper. Unfortunately, many people believe in this dividing line between mentally handicapped people who have sufficient skills to live in the community and the more severely handicapped who are cast in the sick role; as 'patients' requiring hospital treatment.

* Tizard J. 'Community Services for the Mentally Handicapped'. 1964. Oxford University Press.

It was also unfortunate that the very important White Paper, 'Better Services for the Mentally Handicapped'*, which was the first official document to consider community based services for mentally handicapped people, made the assumption that local authorities would care for the more able people and the hospital services would continue to provide services for the more severely and profoundly handicapped.

The outcome of such an assumption is that all the problems of stigma, second rate services and dehumanising conditions associated with large-scale segregated services are simply shifted onto a smaller group of people.

It is our view that such assumptions are invalid and we firmly believe that all mentally handicapped people, irrespective of type or degree of handicap, have the right to live like others in the community and should be provided with the necessary services which will enable them to do so.

Moreover, we have seen from services actually in operation ** that it is possible to provide services for all mentally handicapped people in the community - including profoundly, multiply handicapped and behaviourally disturbed people.

We have learned the importance of a well thought-out philosophy which guides every aspect of service provision. Central to our thoughts and plans are some fundamental principles, similar to those stated in the Jay Report***.

As our starting point we take the ideas already expressed in the King's Fund Project Paper No24 'An Ordinary Life', which sets out what we believe are the important ingredients in planning and providing comprehensive locally based residential services for mentally handicapped people. We have tried to elaborate some of the thinking behind those ideas as they affect the provision of services for the people we referred to as having 'special needs'.

This discussion paper has the following four main sections:

Philosophy - We start with the philosophy, or fundamental principles, which we believe should be behind any service for mentally handicapped people.

Individuality - We believe that the provision of services for people with special needs should begin with the needs of these individuals.

Individual Plans (IP's) - Individual Plans are of central importance in the services we advocate, forming the basis of service provision which aims to meet individual needs.

Staff: Skills, Structure and Support - This discussion paper presents our belief that staff are more important than buildings when providing services to mentally handicapped people.

* 'Better Services for the Mentally Handicapped' 1971 CMND 4683 HMSO.

** Thomas D., Firth H and Kendall A. 'ENCOR: A Way Ahead'. Campaign for Mentally Handicapped People. London. 1978.

*** Report of the Committee of Enquiry into Mental Handicap Nursing and Care (Jay Report). HMSO. London 1979. CMND 7468-1-2.

PHILOSOPHY

The Principles behind Services to Retarded People with Special Needs

This paper is about practical things that can be done for mentally handicapped people. But we believe that good services can only be achieved by looking first at the principles by which people are operating. This paper is based on three key principles:

1. Mentally handicapped people, however profoundly handicapped or whatever additional handicaps they may have, have the same human value as anyone else and therefore the same human rights as all of us.

   Any discussion of the needs of those handicapped people who have 'special needs' must start from the premise that their lives are of as much value as those of anyone else.

2. Services for mentally handicapped people must recognise the individuality of handicapped people. The special needs of mentally handicapped people are as individual and idiosyncratic as the special needs of people in the population at large who have difficulty seeing, hearing, walking, communicating, or who are elderly, infirm or who suffer at times from emotional disturbances.

   All mentally handicapped people are individuals like anyone else. Yet profoundly handicapped people get less consideration for their individual needs than any other handicapped person. In residential services the more able now frequently get the choice of living on their own, in a group home, in a hostel or some other form of supportive environment. profoundly handicapped people and all those who cannot walk or talk, for example, rarely get such a choice. The only residential accommodation offered them is often the chance of living with fifteen, twenty or even thirty people with at least as many problems as their own in a setting designed not for living but for observation and treatment.

3. For people who have some special need for services, living like others within the community is something they have a right to choose to do.

Despite the fact that it is gradually being recognised that mentally handicapped people have the right to live in the community like anyone else often this right is only granted to the mildly handicapped. There remains a high risk that more severely handicapped people will be denied this right. People with special needs who are unable to live at home are almost certain to be removed from their home community and be considered second class citizens.

We are opposed to this sort of segregation which results in many handicapped people being doomed to social and physical isolation in an institution.

A life within the community with the same rights and opporuntities as other citizens is now coming to be recognised as possible for mildly handicapped people, but those who are profoundly retarded, those who are physically as well as mentally handicapped and those who suffer from other disturbances are still in danger of being offered poorer services if they live at home, and of being offered only institutional care when they need a place to live elsewhere.

No single type of provision, no single type of service can meet the needs of all the people with even one of the types of difficulty mentioned in the introduction. Each person has needs in common with many others, but equally each has needs which are particular and will change as time goes by. In providing services for handicapped people with special needs we believe it is the recognition of this individuality that is central to the provision of services for these people.

Research has shown* that when profoundly handicapped people are provided residential care as a group the care given tends not to be individually orientated. The same is almost certainly true for retarded people with other special needs: they receive less individual attention if they are cared for as a group.

There is no-one, however retarded, however disturbed, however handicapped, who is not 'able' to live in the community. There are thousands of mentally handicapped people with grave emotional disturbance, with multiple physical handicaps, who are elderly, blind, deaf or autistic who are living in the community with their parents or relatives throughour Britain. Their lives may not be fulfilling, and the lives of those who live with them may be difficult, but it is strangely often forgotten that there is actually no doubt about the ability of profoundly, multiply handicapped or disturbed individuals to live in the community if parents are available at home. The doubt exists as to whether there is the will and the resources to make this possible for those for whom the local authorities and NHS have taken responsibility. The issue is not what is possible; it is how to provide services which meet the needs of handicapped people.

It is not enough to simply live in the community. The 'community' should be enriched and enhanced with services which will give every handicapped person the opportunity to live as near-normal life as possible. Once again we become aware that it is those handicapped people who are most in need of services who are commonly denied these services.

In Britain there are large numbers of handicapped adults with special needs who live in the community with their families and are denied any form of daily occupation. They are forced to remain with their families 24 hours a day.

By way of contrast we are aware of services in other countries where, for example, even the most severely behaviouraly disturbed adults are never considered too handicapped to have a daily occupation. These brief examples from ENCOR help to illustrate this point.

* Raynes N V, Pratt M W and Roses S 'Organisational structure and the care of mentally retarded', London, Croom Helm 1979; see especially chapter 14. and McCormick M, Bella D, and Zigler E (1975) 'Resident Care practices in institutions for retarded persons: A cross-institutional, cross-cultural study'. American Journal of Mental Deficiency 80 1-17.

Valerie is a severely handicapped woman. She persistently injures herself usually by banging her head. She lives in an ordinary house in the community. In order to do this one staff lives in and others work with Valerie on a shift basis. Valerie would be described as having severe behaviour problems. Valerie is also guaranteed a daily occupation. To give her this right requires a 1:1 ratio during all her day at the training centre but eventually this 1:1 attention will be reduced to much shorter periods.

Terry also attends a training centre. She too is severely mentally handicapped and is emotionally disturbed. She would be considered too 'difficult' to be given a place at many British training centres. She earns $95 (approximately £50) a week for the output she has now achieved in her production line work. Even very disturbed people can do useful work.

Frank lives with his parents but some of the caring is shared with the service providers. A member of staff goes to Frank's home about 30-40 hours a week to help Frank's parents take care of him.

Jane's situation illustrates that a great deal of careful thought and flexibility on the part of professionals may be needed if individualised services are to be provided for some people who have in the past been given/forced to accept only existing institutional provision. Jane has been labelled 'autistic with profound behaviour problems', 'schizophrenic' and 'a danger to others'. Moved from one institution to another, she was finally given the opportunity to live in the community by a court action on her behalf. An experienced adviser worked over months on a plan to provide a service which would allow Jane to live in an ordinary house with helpers. His basic assumption was that Jane's future possibilities would not be understood without exposure to situations in the real world and training there. The steps in the plan for the first year were these:

Prepare foundations of the programme
Prepare for Jane's return from the institution
Expose to the community
Establish a rhythm to her weeks
Provide instruction
Extend social supports

Finally, and only after careful planned exposure to the local community, and only after beginning to provide training and social opportunity, would the plan for the first year be completed by:

Selecting service goals to be sought and service supports to be provided during year two.

Jane is now living in a local community with two companions (employed specifically as a couple to work with Jane). A teaching companion aims to expose Jane to a wider sample of adult culture than she has experienced, to expand her social networks, and to provide both 'work' and leisure, as well as assist her living skills. The teaching companion is also responsible for managing a programme budget on Jane's behalf. A support companion has a good stable relationship of friendship with the teaching companion (they were appointed as a couple to work together) whose job is to live with them, help in emergencies and provide feedback and personal support to the teaching companion. These two employees are supported by a 'programme support team', consulting specialist and sponsoring organisation. The flexibility, individual approach and staff support in this example contrasts starkly with most services to individuals with special problems, but the cost of this service is little different from the cost of the institutional 'care' Jane was receiving.

Because in times of financial difficulty it is those with the greatest handicaps and those whose needs are most difficult to meet who often receive the worst services, we reiterate our first principle: mentally handicapped people with special needs have the same human value as anyone else and so the same rights to a service as good if not better than the services to the rest of us.

When a committment is being made to provide services for all mentally handicapped people irrespective of type or degree of handicap then no one will receive second-rate services or be prevented from receiving services because their handicap is too severe.

Living within the community is a need for mentally handicapped people. Because it is the only way that they can be guaranteed a share in normal patterns of life; it is the only way they can learn from their non-handicapped fellows, and the only way that their fellows can begin to learn from them. Mentally handicapped people develop skills more rapidly when they live with non-handicapped people. The services received by handicapped people who have to live together in hospitals are generally vastly inferior in terms of quantity, and often in quality*. There fore in planning and providing services for mentally handicapped people with any special needs, certain principles must be followed:

(a) No-one should be denied a service or given a second class service because they are considered "too old" or "too handicapped". Services for mentally handicapped people have a duty to be comprehensive. This means that those who show disturbed behaviour, or those who are both deaf and blind, have as much right to locally based services as any other person whether mentally handicapped, physically handicapped, or who have neither of these handicaps but who may have needs for health services or local authority help.

* Maureen Oswin 'Children in Long Stay Hospitals' London, Heinemann 1978.

(b) Services should support, not supplant the networks in which mentally handicapped people are established - whether family, school, work or leisure. All too often when someone has a special need they are moved to a place that can provide for that need. This removes them from all their supporting networks, and may often leave them worse off than they were before. Services should aim to support existing networks not supplant them.

(c) It follows from this that wherever possible mentally handicapped people should not be moved to alternative settings unless they have chosen to do so. It is an almost unwritten asumption in many services for handicapped people that as their individual needs change, they must move from hospital to hostel, from hostel to group home, from group home to flat. We believe it is staff and services, not the clients, who should be prepared to move to meet a changing need.

(d) There should be a constant effort to provide services to people with special needs in the way which is least restrictive possible for the opportunities that person may have.

(e) If services are to meet individual needs they must be flexible. This is rarely so in practice.

(f) Clients should be encouraged to go out and use services which are available to the rest of the community, rather than specialist services for mentally handicapped people (eg dentist, optician, hairdresser). People who live in the community and use generic services actually get better services than those who have to rely on specialist services for mentally handicapped people.

(g) The key feature in any service is its staff, their skills and the way they work, not its buildings. This point we shall elaborate.

There is a very persistant and quite inappropriate assumption especially prevalent within the health service. The assumption is that if a service is needed for a client group, the next step is to commission a building or unit in which to provide the service. This is not the way to provide services for mentally handicapped people with special needs.

It is special skills and special services that these people need, not special buildings or units.

In considering the needs of these people with extra difficulties, it is vital to start by planning the provision of services, especially staff with skills and questioning any assumption that buildings may need to be built. It is only very rarely there is a need for any new buildings.

INDIVIDUALITY

Whilst each of our principles is very important, the issue of individuality is particularly relevant when considering the provision of services for people with special needs. Each mentally handicapped person may have needs and strengths in common with many other people, but equally each may have needs and strengths which are particular and which are a part of that person's individuality.

When providing services for people with special needs it is essential that

(a) the individuality of each consumer of services is recognised and
(b) the services provided are those which meet the individual's needs.

The regular assessment of individuals' needs and the development of a written plan with short term and long term goals (an individual programme plan) is a central component in the services we are advocating and is dealt with in more detail in a later section of this paper.

In a community of 50,000 there will be around 80-90 handicapped adults. Only some of these people will have additional difficulties. Providing individualised services on this scale is quite possible.

We have referred to evidence which shows that when services are provided on a large-scale, as in hospitals, the individuality of mentally handicapped people, especially the most severely or multiply handicapped, is lost due to low staff ratio's, routines and physical inability to provide an individualised service.

By way of contrast when mentally handicapped people are cared for in small groups (five or less) there is more opportunity for staff to become involved with their mentally handicapped clients as individuals, as people who have their own personalities, their own ways of communicating and their own abilities.

In order to discourage dehumanisation and lack of dignity it is essential that the person being cared for is perceived as having a personal identity. Services such as those advocated in 'An Ordinary Life' encourage this.

Some problems in the lives of people with 'Special Needs'

Let us now turn to the people we are referring to when we talk about people with 'special needs'. What problems do they present to their carers and what are the problems which they themselves face?

Problems for the carers In many residential settings there are too few staff to provide the basic elements of feeding, dressing, toiletry and human contact for the number of clients in their care. It is extraordinary that when a situation arises in which two parents cannot provide for their one child, that child is then admitted for "treatment" to a setting where often two adults have to cope with a dozen or more "problem children". There is no way round this problem other than the spending of more money to employ sufficient staff to do the job.

The lack of speech, conversation or recognisable communication from profoundly handicapped people is wearing, unsatisfying, and ultimately demoralising for the care staff. It is very easy for the staff to begin to dehumanise their clients especially if they are so rushed for time that they never really learn their clients methods of simple communication.

Disruptive and uncooperative behaviour on the part of the clients is also very wearing for staff and it is easy for them to become exasperated and irritable, particularly if they are lacking professional skills.

Staff caring for groups of severely handicapped people can be placed under a great deal of pressure. Often they are not given the support or resources they need to cope with these pressures.

Problems faced by the consumers of these services. Again it should be stressed that people with 'special needs' are not one single group of people. They are not all people with similar problems and needs; each varies according to the skills possessed, type, degree and number of handicaps, service needs and support available to them.

The problems faced are a combination of those which are inherent in their handicapping conditions and those which are created, or exacerbated, by their environment.

Lack of basic skills - Many severely or multiply handicapped people are not able to wash, feed, dress or toilet themselves. Some do not have the pre-requisite abilities which are necessary to learn these basic living skills. For others who have the pre-requisite abilities but who learn very slowly the massive input of time and resources necessary to teach these skills has often not been made.

Inability to perform thses basic skills means that the handicapped person becomes dependant on carers and often has little or no say in how and when thses tasks are performed.

Lack of language - Lack of speech or other form of communication is a problem which many people with special needs face. A high percentage have little or no means of describing their needs, feelings or opinions.

Medical involvement - Epilepsy, physical deformaties, diabetes, recurrent chest infections, urinary infections are some of the wide range of "medical problems" which some people have to cope with in addition to their mental handicap.

Sensory Deficits - Total or partial deafness and/or blindness present additional problems for some people, further handicapping them in their ability to master skills and enjoy their environment.

Lack of Mobility - Some severely handicapped people have mobility problems. One group of people who are especially handicapped are those who are wheelchair bound, especially if unable to operate the chair.

In situations where groups of severely handicapped people are cared for together those people who are confined to wheelchairs can never escape their environment, the noise and shrillness, they can't get to the toilet alone or escape the physical assaults of able-bodied co-residents. Similar problems may exist at home if parents dominate and infantilise the handicapped adult. Once again they have no way out and often do not even have any way to express their feelings.

To understand what it feels like not to be able to move about, escape noise or influence the environment in any way, imagined being detained where you are now. Imagine you are wheelchair bound and have no form of communication. All of your activities are directed by someone else who speaks a language you do not understand. You will eat, sleep, go to the toilet and bathe when someone tells you and this regime will continue indefinitely. This exercise might give the reader some idea of the problems faced by many multiply handicapped people.

Dislike of Noise - Some people suffer early childhood autism. They often have as part of their condition a hyper-sensitivity to certain sounds (and sometimes colours) and an extreme level of difficulty with social relationships.

They tend to hate being in crowds, get very agitated with too much going on around them and escape to quiet empty places at the first opportunity. In residential settings, these people are frequently seen as particularly handicapped, and so end up on the most overcrowded and understaffed wards with many other disturbed individuals. Therefore, they are daily forced to experience the very conditions which are almost certain to provoke them also into disturbed behaviour. People in this category almost never have any way of telling us to shut-up and go away.

Psychiatric Problems - Many mentally handicapped people suffer psychiatric illnesses which are unrecognised or undiagnosed. The identification of some psychiatric illnesses requires specialist skills and detailed knowledge of the clients behaviour over a long period of time. Severe depression suffered by severely mentally handicapped people whether as adults or children in particular is often unrecognised. The result of this is that they have to live with the problems of living with an undiagnosed psychiatric illness.

Loss and Grief - Throughout their lives mentally handicapped people are faced with losses of different kinds. Deaths, changes in staffing, movements of co-residents, changes in living accommodation, changes in schools, all these occur but often are not explained to, or are not understood by, the handicapped person.

Mourning for lost parents, friends and relatives, home and lifestyle is very real. The ways in which handicapped people express their grief varies and often grief can go unrecognised. Even when recognised, giving support and reassurance may be very difficult for even the most sympathetic staff to provide.

Insecurity - Being faced with the stresses of a world insufficiently understood, can produce anxiety and obsessional behaviour.

Unrecognised Sexual Needs - The hetrosexual or homosexual needs of mentally handicapped people are often denied expression by denial, by repression or by punishment. This naturally produces frustration.

Lack of Friendship - The many human relationships which we tend to take for granted are all to often denied to mentally handicapped people. Many people with special needs have had little or no opportunity to form relationships with people other than family or staff. The potential for friendship, in which warmth and caring can be shared, is often pitifully small.

These are just some of the problems faced each and every day by people who have little or no control over their lives. Often it is not the handicapped people who are at fault but the environment in which they have been forced to live.

The problems which mentally handicapped people face as a result of their environment are well recognised. Unfortunately in some instances the resultant problem is ascribed to the handicapped person and not to the conditions in the environment which brought it about. For example, stereotyped behaviour, public masturbation or self-abusive behaviour which has arisen due to lack of stimulation in that person's environment is often dealt with as if the handicapped person is the problem.

> Bill is severely brain damaged by a chemical disorder, is very difficult to live with because he is a compulsive consumer of drinks and can be quite aggressive in stealing them from others. This behaviour triggers off screaming, kicking, hair pulling and hitting others by one of his fellow residents. All this makes someone else so severely agitated and distressed with this scene that he is then prone to bite a fourth resident who then runs away. These situations arise where individual needs are not considered.

One reason for "lump care" in which all those being cared for are pushed together is the problem of "lump diagnosis". This is a problem from which many severely mentally handicapped people suffer.

> Paul was presented to the services where he is now cared for with the label of "high grade subnormal with aggressive outbursts". In fact he has four separate sets of problems: He is a slow learner, he is mildly spastic and rather clumsy, he has major body image and spatial problems which hamper his dressing skills and he also suffers from a recurrent hypomanic illness which makes him irritable, over-active and aggressive. Each of these problems is now handled on its own merit and he is now a much better adjusted and much liked person.

The importance of carefully assessing the needs of each mentally handicapped person and providing individualised services cannot be overstated.

When providing services to help severely handicapped people it is important to understand the underlying causes of their problems and not to see all people who present with a particular problem as being the same or needing the same help. Let us consider the following five severely handicapped people:

> Jane is a 40 year old woman who is still dressed in ankle socks and wears a bow in her hair. She carries a doll and speaks in a babyish manner. She shouts and stamps her feet when thwarted which is the mode of expression appropriate to her developmental level of 18 months. This has a developmental cause.
>
> Anne lives with seven other severely mentally handicapped people; only two of whom have any form of communication. Bob, one of the male residents hits staff and other residents when frustrated. Anne has copied this behaviour from Bob and has also copied his habit of wetting and stripping. This is a learned behaviour.
>
> Dave was brought into hospital when his father could no longer care for him. He was in a wheelchair and for a period of time would lash out physically and verbally at staff. Dave had been suddenly removed from his home and family with almost no explanation or counselling. This behaviour was part of his grief reaction. As he adjusted to the new environment the aggressive outbursts reduced.
> This is an example of an emotional response to a situation.
>
> George suffers from a cyclical mood disturbance which periodically results in him injuring himself. He cannot control the mood swings himself but requires specialist treatment for this problem.
> This is a psychiatric problem.
>
> Ivy is an elderly lady who is severely mentally handicapped. She hits and pinches staff and other residents. This is not a behaviour that Ivy has shown all her life; it is of relatively recent onset. Other facts suggest that this behaviour is due to dimentia.
> This is an organic problem.

Although all five of these people act in a similar way, the services each of them need are quite different.

INDIVIDUAL PLANNING AS A WAY TO MEET INDIVIDUAL'S SPECIAL NEEDS

To meet the individual special needs of retarded people, there is a very powerful technique available to help us. This is the individual plan (IP), developed during the 1970's both abroad and in this country*. The concept of individual plans has much in common with the 'Life Plans' discussed in the Report of the Committee of Enquiry into Mental Handicap Nursing and Care (Jay Report)**. The individual plan is not a case conference. It is a plan of action. It states precisely what people will do: either what it is planned that the client will do by the time of the next meeting, or statements about what other people - family, friends or professional staff working with the client - will do by the next meeting.

Some words of caution are required. IP's are not something which can be done without careful planning. A considerable amount of work is required by someone - usually called the key worker or client contact - between meetings. A system of individual planning requires a major service commitment. Individual plans cannot be written as a spare time activity. A service must allow time for the key workers to plan and prepare IP's; the service must also provide a well worked out management system for ensuring that when service needs are identified, many or most of those services are provided. Individual planning is useless unless there are services available or opportunities to meet client's needs. If there is no way client needs can be met and virtually no services available, individual planning will become a demoralising and destructive process, for the staff and relatives involved.

The individual plan consists of three components: work before the IP meeting, the IP meeting itself, and follow-up and review. Before the meeting each client's key worker completes a list of the clients strengths and needs in consultation with the client, the clients family, and staff working with the client. The IP meeting itself is a formal occasion for agreeing plans for the client. Wherever possible the client and members of the clients family should be present. Even if the client is profoundly handicapped and unable to communicate their presence will help to ensure that the clients interests are the main focus of concern at the meeting. The IP meeting briefly reviews the clients last IP record form, briefly reviews the strengths and needs list for the client, and amends this if necessary, and completes the IP record from stating goals to be achieved before the next meeting in clear behavioural terms: who should do what, to what degree of success, under what circumstances.

One of the most powerful attributes of this planning system is that it systematically identifies clients needs for services. It is vital that staff are trained to use the IP system, and that this training stresses the importance of recording needs which may be quite unable to be met under present circumstances. To be an individual planning system, there must be a mechanism whereby all unmet needs are routinely and automatically notified to senior managers responsible for service provision.

It is the abilility to meet individuals' needs with the ability to plan for the necessary services to meet those needs which makes the individual planning system so powerful.

* The best guide to individual planning available in this country is 'Individual Plans for mentally handicapped people' by Roger Blunden, published by the Mental Handicap in Wales Applied Research Unit, The White Houses, 44-46 Cowbridge Road East, Cardiff. £1.

** Report of the Committee of Enquiry in Mental Handicap Nursing and Care, HMSO, 1979, Cmnd 7468-1-2.

STAFFING: SKILLS, STRUCTURE AND SUPPORT

It has already been emphasised that the staff are the key feature of any service. There are three essential requirements if staff are to do a good job:

a) a structure for staff to work in
b) specialist skills appropriate to the needs of the clients
c) the support which is essential to maintain the motivation to do a good job.

The best structure to promote individual client care is one which delegates as much autonomy for decisions about the services available to clients to those working most closely with them. Thus it is vital that trained and untrained staff involved in residential or day-time services are included in the IP meetings which make decisions about goals for the client. The greatest possible delegation of authority for decisions about clients is essential for good individualised care.

Structure is vital in a second way: the definition of individual staff roles and tasks can have a profound effect on patterns of care. There is a great need to develop knowledge and experience on this issue. It is now clear, for example, that defining separate jobs in a residential setting - separate care staff, domestics and catering staffs for instance - gravely inhibits the ability of staff to teach clients and encourage their independance in daily living skills. A much more effective approach is to have one type of staff employed, who do all jobs*.

The individual programme planning described above is an essential element in meeting individual needs by structuring the goals and the work of the staff working with clients.

The room management procedure** which also provides a structure for staff to work within is a very good way of allowing a limited number of staff to develop individualised programmes of training or experience in day care or vocational settings.

Supporting staff is however as essential as structuring the work staff do. Although much is talked about staff support, there is often little idea about how to improve it in practice.

The greatest danger for any service for handicapped people, whether large or small, is isolation. Managers and senior care staff have a particular responsibility to make sure that neither clients not direct care staff become isolated.

* NHS Residential accommodation for Mentally Handicapped People: Operational Policy, Northumberland Health Authority, Morpeth, Northumberland. 1981.

** Activity Periods for Severely and Profoundly Handicapped Adults - Details of the Procedures. Mental Handicap in Wales Applied Research Unit, 44-46 Cowbridge Road East, Cardiff 1980.

Effective managers will need to visit homes or centres regularly and often, and at unpredictable as well as predictable times. Managers must ensure that there are regular and frequent staff meetings. These may include daily meetings to exchange information and weekly meetings of staff which will be particularly geared to staff support. Any service will need some meetings, perhaps monthly, for all staff to meet with managers and other professional workers with a regular committment to the service. Often, meetings are seen as frustrating or not useful. This is not a reason to abandon regular staff meetings: it is an occasion to improve the manner in which they are conducted.

If we are to avoid staff isolation, bad morale and poor services, we must select, and training managers and other professionals in skills to help staff working directly with handicapped people. There is increasing concern with these issues. In the United States there is now much interest in, and concern about staff "burnout" - a detachment from clients which is one particular result of poor support. In Britian also there is increasing interest in support for staff*.

There is a need to define more clearly what behaviour is actually supportive. However, it seems that two factors are most important if managers or outside professional staff are to be supportive: they must demonstrate an ability to get results - to solve problems, to get the resources needed; and they must show good interpersonal skills in communication - including both verbal and nonverbal skills.

People are seen as helpful because they take time with staff, because they listen, because they ask staff their opinions, because they are not cynical, because they show an interest in staff and because they are available. Besides these receptive skills (availability, attention and listening), there are expressive skills which are found to be helpful. These include: actively offering to help, commenting positively on staff work - not taking it for granted; being positive, and thanking staff. There are many other skills which can be described as important aspects of supportive behaviour**.

One issue of particular importance has to do with time. It is almost always helpful for supervisors or outside professionals to spend time with staff as well as with clients. In many services staff are hard pressed, busy and short of time. Yet the most helpful thing is for someone who is busy to give their whole attention to staff while they are with them, however short the time may be. If more of the time available is spent listening than talking, it is probable that members of staff will feel supported however brief the contact may have been.

* An excellent account of the causes and effects of "burnout" is 'Staff Burnout: Job stress in the human services' by Cary Cherniss, Sage publications, London, 1980.

* 'Staff stress in residential work' by Jack Dunham in Social Work Today Vol 9 (No 45) pp 18-20. (1978) is one description of the problem in this country.

** 'Who Looks After the Staff?' H. Firth, Health and Social Services Journal, 1982.

This issue of interpersonal skills occurs again with meetings. Staff who find meetings un-supportive generally do so because the person leading the meeting is described as dominating the meeting. Frequent staff meetings are essential for good staff support. But they must allow staff the opportunity to discuss their feelings, not merely be a vehicle for the ideas of the group leader. Again, the one most critical skill involved is the ability of the group leader or supervisor to listen.

So there is a clear lead to think again about training managers in interpersonal communication skills. The social skills training approach*provides a model for how to do this. Our knowledge of what makes good staff support is growing. Along with providing the right structure to work in, and the staff with the right specialist skills to help handicapped people with special difficulties, we must also supply the support for the staff engaged in the job.

* An excellent guide to training for professional staff in the relevant social skills 'A Guide to Social Skill Training' by Roger Ellis and Dorothy Whittington published by Croom Helm, London, 1981.

CONCLUSION

It is our belief that all human services are guided by a philosophy or set of principles. The philosophy of a service may or may not be written down. In some instances service providers may in fact be unaware of a shared set of implicit principles, nevertheless these principles exist.

Our principles are that services should recognise:

1. The individuality of each mentally handicapped person who in addition has other handicaps or needs.

2. That mentally handicapped people have the same human value as all other people.

3. The needs of mentally handicapped people to have the choice of living like others in the community.

We suggest that the following seven practical guidelines are in keeping with this philosophy:

a) The key feature in any service is its staff and the way they work. Purpose built facilities are not only unnecessary but can act as a strait-jacket on the services to be provided for people with special needs.

b) Specialist services should support not supplant existing provision.

c) Wherever possible mentally handicapped people should not be moved to alternative settings unless they have chosen to do so.

d) Services should be provided to mentally handicapped people in the least restrictive environment possible.

e) Services should be flexible and responsive to changing client needs.

f) Maximum use should be made of services which are available to the rest of the community.

g) No-one should be denied a service or given a second class service because they are considered "too old" or "too handicapped".

In this paper we have demonstrated that it is possible for even the most severely handicapped or disturbed people to live in the community, using examples from services who follow the principles outlined above.

We have pointed out also that it is not sufficient merely to live "in the community". We have referred to the situation in which profoundly and multiply handicapped people live in the community but are denied many of the opportunities we expect in life; things like friendship, a daily occupation, a change of environment, mobility or the support of friends and neighbours. It is not enough for mentally handicapped people merely to live in the community if they are socially isolated and denied the services which would help them to make the most of their lives.

The examples we have given of severely handicapped people living successfully in the community illustrate the need to provide not simply a place to live in the community but a range of types and degrees of support which meet the particular needs of each handicapped person.

Questions are often raised about the cost of a service provided according to the principles advocated. Although few costings are as yet available in this country it is not certain that such a service would be more expensive than more conventional institutional services. In fact a study conducted recently in the United States which compared the cost of a community based system of service provision with services provided by a centralised institution concluded that the community based services were actually cheaper*. However decisions about service provision should be guided primarily by client needs rather than beliefs about costs.

Since a central theme of this paper is the recognition and provision of services to meet the special needs of individual mentally handicapped people it is important that service providers:

a assess and understand individual needs; and

b plan from these individual needs as the basis for service provision.

For this reason the usefulness of Individual Plans has been stressed as a mechanism for ensuring that there are regular assessment of each client's needs and that these assessments then form the basis of co-ordinated service provision. Individual Plans are also a means of systematically recording occasions when the services to meet individual needs are not available. This information on service deficits can then be used as the basis for planning improved services to meet individual needs.

The cornerstone of this paper is a recognition of the need to provide services which are responsive to the individual needs of clients.

We have emphasised that mentally handicapped people with special needs are not one group. They not only have many different personal needs but even when people appear to have a similar problem, each may require different help in coping with than need.

Throughout the paper we have stated our belief that it is special skills and special services, not special units or buildings, which are required to help mentally handicapped people with special needs.

* 'Cost Study of the Community Based Mental Retardation Regions and the Beatrice State Development Center'. By Touche Ross and Co (1980). Published by State of Nebraska Department of Public Welfare with the Department of Public Institutions, Lincoln, Nebraska.