(13 April 1978)

King Edward's Hospital Fund for London

King's Fund Centre

RESIDENTIAL PROVISION FOR ADULTS WHO ARE MENTALLY HANDICAPPED

Report of a one-day conference held on the 13 April 1978
organised jointly by the King's Fund Centre/Campaign for the Mentally Handicapped

Introduction

Chairman: Derek Thomas, Principal Psychologist, Northgate Hospital.

Why do we need a conference? Anyone who has read 'Looking at Life'* will be clear about this. The central question is how we move towards a better quality of residential services for mentally handicapped adults.

Alan Tyne's report makes clear that the quality of what we provide depends on activity at a whole number of levels within health and social services. Services will not improve unless:

our approach is multi-disciplinary
there is proper partnership between members of authorities and their senior officers
there is a partnership between people within the system and those outside it, with consumers and advocates - including the parents of mentally handicapped citizens, mentally handicapped citizens themselves and people who, although 'professionals', are outside the established agency. In Eastern Nebraska, much of the stimulus for change came from people, both consumers and university people, who had no vested interest in the system as it was. (See later).

THE QUALITY OF LIFE

Alan Tyne, Information Officer, Campaign for the Mentally Handicapped. Formerly a tutor in a teacher training college and involved in voluntary work in a mental handicap hospital; has done research into mental handicap hospitals and nursing care.

Peter Townsend has said that a society can be judged by the way in which it treats its most dependent members and this has always been the nub of CMH thinking. We have always been particularly interested in the place of mentally handicapped adults in society.

The 'problem' of mentally handicapped adults seems long-term and intractable: it can seem that there is less hope than there is for children. In addition, we have, in child care, a series of well-recognised and well-implemented standards of practice and of quality of care. There is a well-established body of knowledge on what constitutes a 'family home'. There is no similar body of knowledge for adults.

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* 'Looking at Life', CMH Enquiry Paper 7, Alan Tyne, Price £1.00.

Available from CMH Publications, 8 Church End, Gamlingay, Sandy, Beds.

'Looking at Life'

CMH Enquiry Paper 5 has looked at the quantative aspects of residential services - the numbers of people in different sorts of provision and expenditure*. 'Looking at Life' tries to look at the quality of home life for adults in different environments - hospitals, hostels, group homes and lodgings. It was often difficult to separate the 'residential' service from others provided, because services come in a package - in one place and at the same time. By trying to separate the residential element to see the ways of life places make possible and to record how mentally handicapped people spent their days and lived their lives, was the focus of the study.

CMH believes that any service must be provided around the needs of the clients. This is worth reiterating, as other questions tend to creep in, like 'How do we make the best use of the resources we have?', and 'How do we ensure that staff do not lose security through change?'. We have to pay attention to questions like this, but the first question, on which this study is focused, is: 'How does the service serve the client?'.

Measuring the Quality of Life

Looking at the life of adults is very different from looking at the life of children. Adults are expected to choose their own way of life. If they lead a segregated, austere life because there are no alternatives, then we can say that their quality of life is low. But if a person lives in a well-equipped hostel with sympathetic and knowledgeable staff, but chooses not to mix with others or decorate his room, then the quality of his life is not necessarily low.

'Looking at Life' tries to define outlines, to identify the important variables which affect the quality of life. We are not yet at the point where the details of quality can be measured by awarding points on scales - although others may wish to develop these scales.

The starting point must be: What are people's needs?

There are three ways to establish needs:

1) By asking people what they want and so obtaining a 'subjective' evaluation. This has very great merits; we all too often assume that we know the needs of mentally handicapped people and neglect to ask them what they require. CMH has taken this approach in a series of conferences and shown that mentally handicapped people can tell us a great deal if we listen carefully enough**. As a method, though, this gives emphasis to those who are articulate and skilled in conventional language. 'Looking at Life' tries to find out what people do each day rather than asking 'What do you think about this place?' The former is a more reliable guide and does not exclude the inarticulate.

2) By establishing a 'social standard' and measuring services against this. The problem with this approach is that there is such a variation in social standards - they can be very low.

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* 'Residential Provision for Adults who are Mentally Handicapped, CMH Enquiry Paper 5, Alan Tyne, Price £1.00.

** 'Our Life', 'Listen', 'Working Out', Available from CMH Publications.

3) By looking objectively at need. This means looking at life in terms of how it affects your functioning, what your handicap deprives you of and what compensations you need. There are deprivations of resources: not earning has major implications for your way of life, and there are social deprivations: being cut off by handicap from the social supports we all rely on - from family, friendships and acquaintances. This approach to establishing needs tries to assess how far different residential services offer people a chance to compensate for these deprivations. This was the approach in 'Looking at Life'.

A Check List of Needs

This is the check-list used in 'Looking at Life':

1.0 Day to day needs
1.1 Ordinary
1.11 Sleeping
1.12 Washing
1.13 Dressing and clothes-storage
1.14 Eating meals and snacks
1.15 Daily occupation
1.16 Leisure-time

1.2 Special
1.21 Health-care
1.22 Provision for incontinence or disability
1.23 Protection from the consequences of others disabilities
1.24 Behaviour problems

2.0 Personal Identity
2.1 Culture-appropriate surroundings/facilities/decor/dress
2.2 Privacy
2.21 of possessions and spaces
2.22 of actions
2.23 choosing company

2.3 Relationships
2.31 membership of groups (functional/friendship)
2.32 relations with other residents
2.33 relations with staff
2.34 relations with family and friends

2.4 Activities
2.41 participation
2.42 daily occupation
2.43 coming and going

3.0 Development and Growth
3.1 communications
3.2 relating with others inside and outside the unit
3.3 developing and sustaining activities
3.4 provision for assessment, formal education and training.

A H Maslow's 'Heirarchy of Need' has influenced the way this check-list has been drawn up. There is a heirarchy of immediacy of needs - from those for food and sleep, to the need to relate to other people, to the deeper level of need for opportunity for growing and developing potential. This list can be applied to people with all degrees of handicap; needs are the same, although ways of meeting them may differ. The list also enables us to direct attention to how needs are met both by staff and by residents. The latter is very important, for the quality of life is often determined not by staff but by the residents' own activities.

There is a constraint: the list is not too long and complex as the writer was working on his on his own. But this is also an advantage: individual staff can keep it in their pocket and use it as he did.

The first question is: how does the home - wherever that is - meet a person's day to day requirements? Does it provide for enough sleep, for enough water, for washing facilities, for somewhere to store clothes? Does it provide satisfying meals and can these be adapted to different times and wants? Is there daily occupation - which is a fundamental need and also of great importance in a person's view of themselves? Is there provision for leisure time?

This section also covers special needs, which individuals may or may not have. These special needs include special health care, and dealing with incontinence or physical disability. They also include protection from the consequences of the incontinence or disability of others.

The second section has to do with people's image of themselves - the way that their pattern of life presents people to themselves and to the world about them. Dress and appearance give a person identity and tell the world who he/she is; so does the building in which they live.

Privacy is about control over space, property and relationships with others. Can people choose with whom they are? How far does the place give opportunities for relationships to form? What opportunity is there for functional groups, related to everyday activities, and for small groups and intimate friendships? How far are relationships based on competition? How far are staff enabled to have relationships with the handicapped people? How far does the setting encourage relationships with family and friends? How far can the handicapped people participate in and make decisions ?

Finally, what account is taken of the individual's need for personal growth and development.

The Case Studies

There is a very wide variation within each type of residential provision. The 'collage' approach in 'Looking at Life' tries to bring together the common features: the six case studies presented are a hospital ward, a hospital annexe, two local authority hostels, a small group-home and a private lodging house.

The last of these sticks out as different. It is based on a single place which may not be 'typical'; since then he has visited another where the care and control are benevolent but smothering. The account in 'Looking at Life' raises the question of whether a lodging house is part of a residential service. Some men had been there for three years and were very satisified with the way of life it provided; it was the cheapest accommodation in town and constraints were minimal. Lodging houses, however, are part of another question - that of housing. People who have been at the top of the heap in the 'care' market fall to the bottom of the heap in the 'housing'market. There is an argument here for enabling all mentally handicapped people to retain a place in the housing market.*

Seven Features which affect the Quality of Life

From visits to some 100 places where mentally handicapped people live, seven features emerged as affecting the quality of their life:

1) The total human and material resources available to the unit.

Many units were starved of resources of different kinds - which raises a question not so much of 'costings' of different units, but of how much of the available resources actually get through to 'ground level'. Perhaps highly centralised services tend to trap resources at the centre; perhaps large living units absorb much higher costs in administration than small ones, as well as in centralised services. Small units dispersed in the community often seemed able to command higher staffing levels than units which were grouped together on big hospital sites.

2) The ability of staff to control and manipulate their available resources at unit level.

Similar resources could purchase a very dissimilar quality of life, and where staff were able to manipulate these resources, the quality of life was usually higher for residents. Where they were not able to do this - which was all too often - the quality of life could be very bleak.

3) The size of the living unit.

Once it was larger than an ordinary family, there were serious deprivations of privacy, a decreased sense of security and considerable intrusions on the kind of life people were able to lead. In a large unit, the disruption caused by one severely disabled person could be very great for all the others.

4) Where the residents were less dependent, the quality of life was higher: residents brought their own resources.

5) Where the unit was able to select its own residents, the quality of life was higher than where it couldn't.

As long as one part of the service can pick and choose who it admits, there must be another part of the service which rejects no one. This leads to two levels of quality of life and a 'double standard' of service. The solution must be that all residential units must serve their own catchment area, without the option to reject residents.

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* A further discussion of housing policy and mentally handicapped people is in 'Mental Handicap, Housing Need and the Law', by Alan Tyne, Price 15p, available from CMH Publications.

6) Support to staff.

Managers were too often seen as negative and hostile, ready to check the use of resources but not to offer support. Staff had conflicting views - they said others couldn't help them but were at the same time pleading for support. They were very isolated and depressed. We need to redefine the role of management so that it helps people evaluate their work rather than simply checking time-sheets and so on.

7) The role definition of staff.

Where staff saw themselves as teachers and educators in the broad sense, it was likely that the living unit would give residents greater opportunity for development and growth. But enthusiastic projects often ran quickly into difficulties because staff could not set goals or evaluate either their own activities or those of residents, and this left staff bitter and negative. The training they had received often seemed irrelevant to the way they saw their role. The built-in monitoring and evaluation of their work by colleagues from outside the unit, so essential to the growth of a service, was almost never provided.

Conclusion

Our residential service is oriented to the provision of units, set up to do such and such a job, and not to the provision of a service to individuals. We set us buildings and leave their staff to decide who they can serve, rather than asking: 'Who needs a service and how can we provide it?' The alternative to present approaches is to say: 'We will provide a home to replace your own and a whole range of other services to enable you to cope in it'. If we did this, we would not group together people we feel have 'common problems' - like 'the severely handicapped' - and who in fact do not.

Points from discussion

There seemed to be general agreement that 'Looking at Life' had the ring of truth - that it described not what should be happening but what actually was happening. The role of management was seen as vital in any move to a higher quality of life for mentally handicapped people. At the moment, it seemed, management was getting between front line staff and clients, instead of helping staff. Staff themselves had tremendous problems in identifying with a broader service and this, Alan Tyne felt, was a reflection of the structures we have set up. Management could be obsessed with saving money rather than helping people turn a mirror on their own work. The service was organised in an isolated way and people in individual units had to select their own residents, because they were swamped with demand and no guidelines had been given.

This central question of selection of residents led one person to ask what were the criteria that should be used to decide that an individual should be in hospital. Was there any reason for dividing the residential service between hospital and local authority, or should everyone, in fact, be provided with a home by social service departments? If so, asked another person, how do we start from the large hospitals and nursing service we have and make the transition? There was, Alan Tyne felt, an immense potential for change in the hospitals - although staff recognised the limitations of large sites and buildings. Given a brief to provide service, the first questions must be: who are the people who need services? what are their individual needs? how can we meet these needs without cutting them off from the resources they already carry - their families, the people who know them in their own area - but rather by building on these resources? If the 'Looking at Life' check-list was used on new hospital buildings - like the 'Peterborough units' - we would find that there are many questions about the quality of life in new hospitals as well as in old ones. This means that we may have to develop residential services from hospitals - or develop a completely different type of service. The latter solution, however, is currently resisted for policy - though not practical - reasons.

It was pointed out that we could have joint services provided by health and social service authorities without necessarily having joint administration. But, as Derek Thomas added, that didn't solve the question of boundaries between health and social service provision, which was exacerbated by national policy. To which one person muttered 'The White Paper is the biggest problem we have' - and seemed to find a fair measure of agreement.

The question of 'large numbers' of people discharged from hospital to 'swamp' specific areas like Thanet and live in unsuitable setting was raised. Alan Tyne doubted whether this was a serious national problem - though it was certainly a local one in a few areas. He reckoned that it had involved maybe 1,000 people in the last five years. At the last count, there were 831 in registered lodgings.

ENCOR: A DIFFERENT APPROACH TO RESIDENTIAL SERVICES

Ed Skarnulis, assistant Professor in the Department of Family Practice in the University of Nebraska, Omaha. Has been director of social work in a State institution for mentally handicapped people in Iowa and worked for the Eastern Nebraska Community Office of Retardation (ENCOR) as director of family resources and then director of residential services between 1971 and 1975.

When Itard became disillusioned about the possibility of creating the perfect human being, after his work with Victor, his student Sequin was more optimistic. He went to the United States and in the early nineteenth century worked with Howe to set up schools for the training of mentally handicapped people. These were small - of between 20 and 30 people - and in metropolitan areas so that people could remain near their own families and have what we would today call normal role models.

After a few years, however, there was a move away from this developmental model. People became pessimistic when mentally handicapped people did not meet their high expectations of them. So the approach became protective; influenced perhaps by the romantic poets, institutions were set up in the country for the benevolent protection of "God's holy innocents".

With Darwin's work at the end of the nineteenth century, the emphasis changed again, this time to the protection of society from the propagation of defectives. This was further encouraged by the influx of immigrants from Northern Europe, between 1890 and 1910, who were seen as an economic threat. They dressed and talked differently, and so they got cast as deviant - a category into which mentally handicapped people were also put. A "scientific" study of a family called Kallikak seemed to prove conclusively that defectives bred defectives - although today its reasoning is clearly completely false, it had tremendous influence at the time. The eugenic scare it started is echoed in laws across the United States for the sterilisation of mentally handicapped people.

So the State institutions grew, to protect society from its defectives. The period from 1910 to 1950 was one of despair for mentally handicapped people. There was no rationale at all for the growth of colonies and villages, which superintendents bragged they could run on "high-grade" labour. 1950 saw the peak of the numbers in institutions - although this was never more than 3% of the population. For parents, the option was either to keep their child at home with no services or to send him to a distant institution. These options were intolerable and the National Association for Retarded Children started, to fight for the rights of parents and of handicapped people. Today, it is the largest single voluntary organisation in the country - very vocal and very strong.

During the 1960's three things happened to change the pattern of service to mentally handicapped people. First John Kennedy admitted that he had a mentally handicapped sister, then Hubert Humphrey that he had a mentally handicapped granddaughter: it became almost fashionable to know someone who was mentally retarded. Secondly, David Vail published "Dehumanisation and the Institutional Career" *, which showed how institutions were run for their own convenience, and outlined a concept of "dignity" which was the exact opposite of

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* Illinois, Charles C Thomas, 1966

current institutional practice. This came as a bombshell. Parents of people in institutions determined that they must change these institutions and much diligent work was done to upgrade them. And finally, in about the middle of the decade, the concept of "normalisation" began to arrive from Scandinavia. NARC visited Scandinavia and began to press for community-based services.

ENCOR - Basic Beliefs and Beginnings **

The same pattern developed in Omaha, Nebraska - a conservative Republican city. But people did believe in local control and taking care of their own - especially if this turned out to be cheaper. In 1968, professional people and parents got together to develop alternatives to the State institution and laid certain groundrules which are particular to ENCOR.

1. All staff will train in the philosophy of normalisation - which is positive and the best we have.
2. All human beings are capable of growth. If the people we serve don't develop, it is not a function of their handicap, but because we do not have the techniques to help them.
3. We will serve ALL mentally handicapped people from the catchment area, no matter what their problem. (There are some 18,000 people in the area with mental handicap, although the vast majority of these have mild handicaps and we reckon that only 10% of the total need services).
4. All services will be provided in the community - our intention is to close the State institution.
5. The dignity of reasonable risk must be recognised as essential to the individual's growth and development.
6. We must support, not supplant, the natural home and provide the least restrictive alternative. We will not, for instance, provide a 24 hour a day, 7 day a week residential facility when parents only want part-time relief.
7. Services will be comprehensive - day programmes and dignified work must be provided.

ENCOR began in 1970, as a Government agency funded from local, State and Federal sources. It started when the parents in the Greater Omaha Association for Retarded Children (now Citizens) (GOARC) decided that it was impossible both to provide and to monitor services and opted for the latter.

ENCOR's first priority was vocational services. It set up industrial training centres, work stations in local industry and job placement schemes. Then it concentrated

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** An account of ENCOR's development and current services is in "ENCOR - A way Ahead", Price £1, Available from CMH Publications.

on building services to children - primarily day care, as there was then no public education for the severely handicapped. (This was introduced in 1975, and now all mentally handicapped children are integrated into ordinary schools.) In 1972/3, ENCOR set up support services to families - including medical and psychological help, transport and recreation. Then in 1973, it started to concentrate on residential services.

ENCOR's Residential Services

At first, it was thought that staffed group residences for between 6 and 10 people would answer all problems. But these homes brought problems of their own.

* staff worked impossible hours and lacked status and privacy.
* it took nine months to set up a home.
* the cost was becoming prohibitive - fire and other regulations added to this.
* neighbours complained about the homes being there.
* we knew that the greatest attention went to the "problem" residents, so some were neglected.
* the parents felt displaced by the staff of the homes and the terminology of "group home parents", "foster parents".

There were two alternatives to the staffed group home. The first were "developmental homes" (foster homes) for children. But ENCOR offered too little pay for many people to take in children and not many were found a home of this sort. The second alternative was staffed apartments for adults. But again, these met the needs of only a few. At that time, ENCOR still had "exit" criteria which people had to meet before they could move on from a group home - with the result that those who most needed a normalising environment were kept in a larger group of residents.

So in 1973, ENCOR started to ask: Why do we have residential services? How do we provide the least restrictive environment? We aimed to support, not supplant, the natural home. For children, we asked parents: "What do you need to help your child develop at home?" We started to provide baby-sitting, counselling, in-home teachers, aids and support to parents. For adults, and children not living in their own homes, we started to offer normal, inter-dependent living. We discovered that it was less expensive to bring backup into that home than to move the person elsewhere.

So ENCOR developed the concept of Alternative Living Units (ALUs). No two are alike and there are no set rules to govern them. They vary from a home with an existing family to an apartment shared with "home teachers", to independent apartments with visiting supervision. A construction worker and his wife, for instance, have welcomed two mentally handicapped children to live with them and their own four children. A policeman and his wife have welcomed two teenage boys. Three mentally handicapped adults are living with five home teachers, for intensive training. Two men are living in a shared apartment, with visiting supervision. A young woman has moved in with a widow. In July 1977, there were 32 ALUs for 53 children and 64 for 110 adults. The group homes have become known as "core units" or "training hostels". There were seven for 31 children in 1977, and the same number for the same number of adults.

People said that ENCOR couldn't set up enough residential places - but between June and December 1964, it created 110.

They said ENCOR couldn't cope with medically fragile children - but it established the Developmental Maximation Unit and many children have moved through this to more normal settings.

They said ENCOR couldn't cope with multiply-handicapped adults - it set up a programme for them.

They said none of this could be done cheaply - but ENCOR's costs are below most others.

They said ENCOR couldn't serve severely and profoundly retarded people - but some three quarters of its clients are in these categories.

They said ENCOR couldn't keep people out of the State institution - but not one person was admitted between 1973 and 1975.

They said ENCOR couldn't serve emotionally disturbed children. It set up a Behaviour Shaping Unit which it closed when it found out that it had become a Behaviour Sharing Unit - and the children were absorbed into other, more normal, settings.

In 1975 the Governor of Nebraska said ENCOR couldn't work without money - and he was right! Since then, it has had to contend with severe funding problems. No single service ENCOR provides is "the best" - everything it provides can be matched or beaten by someone else. But what it does do, is provide a comprehensive community-based service.

Points from the Discussion

- Who is left in the State institution?

At first, ENCOR brought the more able people out of the institution, thinking that they would be easier to serve. That is not necessarily true; their problems may be different from those of severely handicapped people, but they still have problems. It is often easier to cope with a skill deficit than an emotional problem. So the 250 or so from the ENCOR area who remain in the State institution - and more than that have been brought home - have different degrees of handicap. And ENCOR serves the cross-section of people of differing abilities who would typically be found in an institution.

- Has anyone returned from ENCOR to the institution?

Only three people, and that was because ENCOR's financial problems meant it could not provide what they needed.

- What about the people with psychosis, severe behaviour disorders and psychiatric illness?

ENCOR set up a Structured Correctional Programme for those who had been in trouble with the law. The agency uses community health centres for both out-patient services and in-patient ones if necessary; at any one time, there are about four people using the latter. ENCOR's funding problems have meant that some people are not getting the best services possible; some community psychiatric settings can't cope with non-verbal people.

Those categorised as "criminally insane" need a special structure. They can either be physically removed to closed buildings, or provided with enough skilled staff to control their behaviour which is very expensive. Whenever possible, ENCOR will provide the staff - sometimes as many as four people to one individual in an intensive programme. Fortunately, these "criminally insane" people only form a minute proportion of the total population served.

- Where does a child go when his parents can no longer look after him?

ENCOR serves all mentally handicapped people according to their individual need and will find alternatives to the family home. GOARC now has a guardianship programme, so parents can take the places of a child's own parents.

- Is a child who is fostered among normal children happier than one who lives in a small, special home?

Alternative Living Units are not a "type" of provision. If an individual needs contact with another mentally handicapped person, that is what ENCOR will provide. Most studies of mentally handicapped children show that they develop better with normal children than with other mentally handicapped ones.

- How are foster parents recruited?

They are not foster parents - they are trained "home teachers" for children and "residential associates" for adults. They are recruited through newspapers, radio, TV, bumper stickers and the parent organisation - and also through word of mouth. Sometimes members of staff in a core unit becomes so intrigued by a client that they move out with him/her.

- How are ALU staff trained?

ENCOR offers a basic 32 hour training in first aid, cooking, nutrition, the philosophy of the service, behaviour modification and precision teaching and such medical knowledge as is needed. Then the individual works with the specific individual he or she will be serving, in the core residence, before moving out. The concept is not one of an overall "training programme" but of training one individual to help meet the needs of another individual.

- What happens if an ALU breaks down?

Ideally, ENCOR would try to keep the handicapped person there, providing staff support from the core unit. If this is not possible, then the person will have to move back to the core unit - which he/she already knows - until another ALU can be found.

- What are the costs of an ALU?

Staff costs can vary from $1 a day for a friendly visitor to $1500-2000 a month for a live-in associate with a PhD in psychology. On average, the cost of providing a place in an ALU is $14 a day - compared to $20 a day in a group home. ENCOR has been worried that this means the first service is too cheap - but costs are now rising.

- What about waiting lists for ENCOR services?

There are no waiting lists - except for the 250 or so people still in the State institution and about the same number unsuitably living in nursing homes.

- What about quality control of ENCOR services**

A serious criticism of the Development Team in England is that it lacks a well thought-out and publicly available evaluation index. ENCOR uses PASS (Programmed Analysis of Service Systems) and has sought to ensure good quality control by making parents as informed as professionals. It has an advisory committee composed of parents, who are able to take the same training as staff. Each facility also has an advisory committee which includes parents. A contract is drawn up for each person who comes into ENCOR services, covering items like how long they expect to stay, what improvements are wanted and who is responsible for the details of helping them. Each person has an Individual Programme Plan which is reviewed every six months and parents always attend reviews if they wish. Half the board of the Greater Omaha Association for Retarded Citizens is made up of parents.

Points from the Syndicate Groups

Some Blocks to Progress in England

- a lack of collaboration between professional agencies: the hospitals don't want to let people go, particularly if they are severely handicapped, and the local authorities don't want to know them.

- a lack of collaboration between professional agencies and "advocates" - some CHCs are not allowed to visit social service department facilities, while others are.

- a lack of collaboration between professional agencies and local people - neighbours don't support a group home, for instance.

- a deep lack of agreement about the sort of services we want to see. Some people believe in a hospital component to residential services, others do not; some believe in "village communities", others want a comprehensive locally based service for *all* mentally handicapped people.

** A paper on ENCOR's advocacy and monitoring programmes is available from Alan Tyne, CMH, 96 Portland Place, London W1.

Some Pointers to Progress

- the importance of starting with support to families: day and short-term care, relief care, foster care.
- the importance of using housing associations and renting houses for adults.
- the importance of listening to mentally handicapped individuals and involving them and their parents in planning.
- the importance of informing CHCs, who can promote the interests of mentally handicapped people.
- the importance of using existing resources flexibly: nurses working outside hospitals, for instance.
- the importance of providing a high staffing ratio for the most severely and multiply-handicapped people.
- the importance of choice for parents, in whether or not their handicapped child stays at home.
- the importance of adolescents learning social survival skills at ATCs so that they can leave their family home.
- the importance of volunteers in the widest sense - the milkman, the people who run the corner shop.
- the importance of the provision of day services keeping pace with the development of community residential services.
- the importance of appointing one person, probably a parent, with responsibility for co-ordinating all the services to mentally handicapped people in a given area.

Some Unanswered Questions

- How can we reflect the aspirations of the front-line careers - parents and staff - for greater autonomy?
- How can we maintain morale among staff in a period of transition?
- Is it right to move people on continually through different residential settings which cater for "one group"? Would it be better to provide a permanent home and offer varying degrees of support as needed.? Can we afford this?
- How far should we start from the resources we have and how far from a commitment to an explicit philosophy, as ENCOR did?

A Final Thought

Derek Thomas: We probably have to move quite dramatically from our present labelling of one group of people as "severely and profoundly retarded" and another as "less severely handicapped", to finding ways to meet the needs of individuals. ENCOR's network of services provides a unique solution. It has a unique way of using human resources - both the professional resources which we in this country could be using far more effectively, and the community resources, the people who could, in this country, be caring for mentally handicapped people in a creative and individual way.