Needs and Opportunities in Rehabilitation

Rehabilitation in psychiatric conditions: 1—Community and residential care

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Each morning 80 women queued up to have their hair combed.¹ Few of them possessed a comb and few perhaps would have used one anyway, because action had been extinguished by years of the institutionalism that was common in some large psychiatric wards a few decades ago (and indeed may still occur even in other settings). Wing and Brown describe how in eight years many of those women had improved; there had been reorganisation and patients had less time doing nothing and less restriction. Some, even of the most severely disabled people, had actually left hospital.

"Deinstitutionalisation"

"Deinstitutionalisation" began in Britain in the mid 1950s, when some 150 000 patients were in mental hospitals and inpatient units; since then around half the beds have disappeared,² and some of the remaining patients are there only because suitable facilities are lacking in the community.³ Successful treatment with psychotropic drugs clearly paves the way for rehabilitation and resettlement. But resettlement does not imply that ex-patients have been rehabilitated.⁴ Some were discharged—and still are—after inadequate preparation and ended up with a life of isolation and emptiness, even destitution or prison. Nevertheless, few people, said a psychiatrist, want to stay in hospital if they can manage outside. Other ex-patients have found the new community care a reality. But the recent Social Services Committee report concludes that the cart has been put before the horse: the pace of removal of hospital facilities has far outrun the provision of community services to replace them.⁵ A hundred or so large mental hospitals remain and the Department of Health and Social Security predicted in 1975 that in some areas they would have a major role for another 20 years.⁶ But in Oxford, for example, resettlement is virtually complete and only 63 long stay patients (13/100 000) remain (G P Pullen, personal communication). Many mental hospitals have excellent facilities and enterprising approaches to treatment and rehabilitation; but there are still some with patients who are mute and incontinent. Many longstay patients suffer from schizophrenia, with severe disabilities such as inactivity, poverty of speech, and social withdrawal, arising in varied combinations from their illness and from being institutionalised.⁴

The new chronic patients

New long term patients, however, are still joining the hospital population. Many others have been in hospital for only brief periods

or have been cared for entirely in the community but have longlasting problems and make heavy demands on services. A census in Camberwell in 1979 suggested a prevalence of 139 long term patients in the community per 100 000 total population, compared with 160 long stay inpatients.⁷ The chief diagnoses are schizophrenia and affective disorders, often with a poor response to drugs. It used to be thought that community care would do away with the long term social disadvantages linked to institutionalism. This has not happened. For one thing, people may become institutionalised, in the sense of being dependent, inactive, and understimulated, outside hospital—at home, in hostels and other sheltered accommodation, and even in day hospitals and centres. Furthermore, thanks to scarce resources, community care sometimes means no care, or very little. But even with apparently good management some patients remain severely handicapped and cannot survive without support, though few these days need be long in hospital. Many others have milder handicaps and make only brief contact with the services. They may not be thought to need rehabilitation, yet some struggle miserably through life even though counselling and psychological techniques would often help.

Without proper coordination the services for long term patients—whether the newer ones who are cared for largely in the community or the old ones who are making their way out of hospital into the community—may be fragmented. The network of hospital inpatient and outpatient services, day hospitals and day centres, various forms of sheltered accommodation such as half way houses, group homes, and hostels, and patients living at home are the concern of health and social services and voluntary agencies, and many different workers. The importance of having one person, probably a doctor, responsible for long term follow up once a patient is discharged, and of continuity of care whatever the setting has been strongly emphasised to me. In Oxford once a new patient is accepted essentially the same team is responsible—and the commitment is for life—whether he or she is in hospital, in a hostel, or at home. The average length of readmissions last year was 11 days, perhaps reflecting the success of the system.

What does rehabilitation mean?

Much is now known about rehabilitating patients with psychiatric disorders.^{4,8,9} In the past patients were apt to receive total care regardless of their actual needs; now the emphasis is on giving the minimum support needed to maintain functioning, with the aim of increasing independence. Assessment is fundamental; strengths as well as handicaps must be precisely and regularly assessed and an individual programme with step by step goals worked out. A systematic assessment procedure, such as the Marlborough Assessment Procedure in the Oxfordshire psychiatric rehabilitation service, is helpful for identifying assets and weaknesses, formulating intervention plans and implementing them through different members of the team, and evaluation and reassessment. A basic

principle is that situations leading to success, confidence, and self esteem must be sought through work, domestic, and social experiences as appropriate. The environment rather than—or as well as—the person may need to be changed; but environments are constantly shifting, which is one reason why psychiatric rehabilitation must often be a continuing process.

Clearly some people will never be resettled outside hospital or employed, but rehabilitation is still worthwhile. In one survey rehabilitation was said to be not possible for 43% of a population of new chronic patients.¹⁰ But this is to take “rehabilitation” in a narrow sense, with the risk that little will be done to improve quality of life in the worst cases. Those concerned with psychiatric rehabilitation believe strongly that something can always be done—if only to prevent deterioration. There is the image of a ladder, but this can mislead as some will never reach the top.⁴ A staircase with various landings or resting places is a better analogy that I have heard. Then the aim must be small steps upwards and preservation of the “best level possible” given the handicaps—“a humane and dignified task,” as the Royal College of Psychiatrists puts it.¹¹

The main problems are of five broad types: shortage of good facilities, notably day care places and sheltered accommodation in the community; lack of interest by many professionals in “untreatable” patients; the inadequate rehabilitation content of much hospital and community care, including a slowness to try out some promising psychological approaches; the difficulty of carrying over the progress made in one setting, such as hospital, to the outside world; and the poor prospects for finding or keeping a job.

Day care

In the survey by Wing and Brown the most important factor in the improvement of schizophrenic inpatients was having less time doing nothing; an independent factor that helped negative symptoms such as withdrawal was less restrictiveness.¹ In practice, a helpful rather than damaging setting is easier to provide through day care, though it is not guaranteed. Keeping people in the community is also important for avoiding disruption of social ties and normal roles so far as possible, and easing the path back to ordinary life—though it may fail to work in these ways unless specific help is given. In addition, treatment and support, “asylum,” and respite for (and from) relatives can often be given just as well in a day hospital or centre.^{2,9}

Camberwell provides a good example of community services (with short hospital admissions if necessary) based on a day hospital, local authority day centres and services, sheltered work and accommodation, and so on.⁷ The District Services Centre, opened in 1981, provides a focus, separate from the nearby Maudsley Hospital, for comprehensive facilities for severely disabled long term patients. A study of day hospital patients in Cardiff, less well provided with varied community services, showed a lower prevalence of long term patients using the services, and high rates of mental and physical symptoms.¹²

Day care is said to be of uneven distribution and quality and inadequately evaluated, and its opportunities are not sufficiently exploited.^{13,14} Day services¹⁵ are provided by health and local authorities and also by voluntary bodies, day hospitals being in theory more devoted to treatment, including occupational therapy, and day centres having more of a social and recreational and sometimes work function, though they often overlap considerably; both have many long term attenders (Edwards and Carter¹⁷). In 1976 the equivalent of 100 day hospitals and 800 day centres—over 30 000 places—were missing, according to Edwards,¹⁶ on the basis of the DHSS guidelines⁶; and this shortfall has not been vastly reduced since then.

The most important task is to form relationships with users, said two fifths of staff in day hospitals surveyed, three fifths in social service day centres, and four fifths in voluntary centres.¹⁷ Though it does not follow that the rest neglected this task, the quality of interaction does vary. In one survey of day centres warmer interaction and a more personal approach to problems was found to

We wholeheartedly support a policy of community care for mentally disabled people. It cannot be put into practice overnight. It cannot and must not be done on the cheap. If it were, the effects on thousands of our most vulnerable fellow-citizens could be disastrous. We must ensure that people with a wide range of mental disabilities receive care at least as good as that which they at present receive, and preferably better. That involves a lot more than reducing the number of hospital beds. It means the creation of a wide variety of alternative facilities. It means providing supportive services for those many mentally disabled people who currently have little contact with statutory services, and for their families. It means that the rest of the community has to be prepared to accept mentally disabled people in its midst. It means the redeployment of thousands of skilled, partly skilled and unskilled staff, and a switch of capital resources. None of this is cheap. It is no good imagining that community care will save money. Nor is it easy to plan and implement. The frontiers are still relatively unexplored. . . . In the final analysis, the outcome will be judged next century, neither by the location of care, nor by the nature of the agency providing care, nor even by the category of staff concerned, but by the quality of care available and the extent to which individual needs are catered for.

From report of Social Services Committee,⁵ para 223

go with “client centred” rather than “institution centred” management (for example, dealing with clients as a group and making a social distinction between them and the staff); traditional custodial methods in the new settings are clearly a danger.¹⁸ Unexpectedly perhaps, day hospitals linked to district general hospitals were found by Edwards to have less flexible and more institutional approaches than those of mental hospitals.¹⁶

It is not sufficiently clear which features of day units are helpful.¹³ In a comparison of two day hospitals the more “directive” programme, focused on various therapeutic activities, seemed to be effective, but not the programme emphasising “non-directive” social interaction.¹⁹ In an American study chronic schizophrenic patients were less likely to relapse (and had their symptoms reduced) with prolonged attendance at centres providing occupational therapy and recreational activities—with “sustained non-threatening social support”—than those who went to day centres with a high turnover of patients and with group therapy and individual counselling, which perhaps led to too intensive interpersonal stimulation for these people.²⁰ In some voluntary centres, such as one I visited in Richmond, clients sometimes become workers and the mingling of helpers and helped is salutary (Wade; Osmond¹⁷). Encouragement and praise and experience in social roles plus novelty and change are ingredients of high quality care suggested by Shepherd⁹—applying obviously to all types of care though more difficult to cater for in large hospital wards.

Some evening and weekend activities are laid on by the Richmond centre, and one man I met there, with severe depression and long unable to work, took part in nearly everything. Voluntary groups can provide such things more readily than statutory services. Even a place to eat and chat can be a lifeline (see Wilder,⁸ p 129), and every district needs to encourage something of the kind. The registers and publications of “Good Practices in Mental Health” (67 Kentish Town, London NW1) list all sorts of community facilities, both voluntary and statutory, using modest resources. Ekdawi points out that users of day units may lead lives that are more impoverished than in the institutions some of them used to inhabit, and that day units must therefore be concerned with how their users spend the rest of their time⁶ (p 98).

Residential care

The facilities of large mental hospitals may create a good environment; at Netherne Hospital in Surrey, for example, rehabilitation practices permeate the whole hospital and there is plenty of scope for participation and activity right from the start, laying a basis for the good results later in terms of resettlement and employment. But in a big hospital the system can work against rehabilitative practices: it may be difficult, say, to do the cooking as distinct from having sessions in an occupational therapy kitchen. At Friern Hospital a ward is being turned into an intensive rehabilitation unit for severely disabled patients. This will have some of the features of the Maudsley Hospital's "ward in a house" for new long stay patients,²¹ though it will inevitably lack the homely atmosphere of 111 Denmark Hill, which is a house looking on to the street but with its back door opening on to its own garden within the hospital grounds.

In this prototype hostel ward for 14 new chronic patients, set up in 1977, there is a high staff ratio, less restriction than in hospital, and scope for domestic responsibilities.²¹ The aim is not necessarily resettlement in the community, and four of the original residents are still there. But more recently a group home (supervised by hostel ward staff) has been opened for six or seven residents from the hostel ward. This has proved most successful. Far more behaviour problems were seen as needing intervention by staff in the hostel than in hospital wards of similar patients—most strikingly in connection with "occupation during working hours" (everyone in the hostel has to be active during the day). The hostel staff have also made particular efforts to improve social interaction and have succeeded in creating "resident oriented" practices and in being relatively accepting and optimistic.²²

Staffed half way houses that assess and prepare their residents for independence have become established,²³ though not as widely as they should. I visited one attached to Goodmayes Hospital in Essex staffed by occupational therapy helpers, motherly women who guide the residents in running the household and shopping and in getting on with one another.

Sheltered accommodation

Lightly supervised hostels, group homes (figure), "sheltered" flats, and so on are not expensive to provide yet in many areas do not meet the need; there is more scope for jointly funded schemes.

Living in the community. This group home, run by Springboard Housing Association in the London borough of Newham and now in its second year, provides long term homes for people with psychiatric conditions. Most of the residents first had a spell in one of Goodmayes Hospital's half way houses to relearn social and domestic skills as they had been in and out of hospital for many years (36 years in one case). The home consists of a converted Victorian house, which includes a communal kitchen and dining room among its facilities, with self contained single flats and bedsitters built on to it. Residents furnish their own flats and rooms, sometimes with the help of a DHSS grant. Workshops are being developed in the basement. There are two full time members of staff plus a part time cook.

Oxford has over 40 group homes, self financing except for staff salaries, and providing strong mutual support for long term patients.²⁴ But too often the various residential schemes may be settings for just sitting around drinking coffee. Ryan found underactivity a problem in both long term hostels and group homes and suggests that residents should attend day centres, if they do not work, for whatever training is appropriate.⁸ He also found a lack of close social contact in both settings, and 53% of conversations were brief and formal. Light supervision and a permissive atmosphere may mean failure to give support and guidance. But some short term hostels are run as therapeutic communities, and some have staff trained to use psychological techniques.⁸

Some people in the Camberwell survey were thought to be inappropriately placed, whether in residential accommodation or in day care.⁶ The need was nearly always for a setting of "lower dependency," and clearly regular review is called for.

Individual programmes

"There is all the difference in the world," a psychiatrist said to me, "between being able to cook and being a cook"—in other words, the emphasis must be on normal roles, and psychiatric rehabilitation should be about the roles and interactions rather than just the activities of daily living. Unless the setting is fairly normal or realistic—for example, an ordinary house—the gains made in rehabilitation may well disintegrate later.

Providing the best settings for each individual to practise or develop his or her roles should be fundamental to any rehabilitation service, but ideally it needs plenty of facilities—domestic, occupational, and so on—from which to tailor individual programmes. The Maudsley hostel ward is an example of the detailed approach to building up the functioning of severely disabled people—it has the modest aim of preventing deterioration or making small improvements, and the staff have check lists for each person based on the psychologist's assessment. One of the residents, for example, when I visited there had to concentrate, with unobtrusive supervision, on practical things such as time of getting up, washing herself and her clothes, and tidying her room before being taken to the workshop. Another received a 50p reward for each workshop session he put in and a small fine every time he used obscene language, and his records showed improvement on both scores. Systematic monitoring shows up what works and what does not. This kind of behavioural approach is not, of course, new but it is difficult to put into practice with these patients. It could perhaps be used in a limited form for less disabled people at home if relatives had enough advice and support; the psychologist thought that it would be useful at least for relatives to work out a consistent routine, have achievable expectations, and give help consistently and in a way that might foster some independence.

In the next article I will touch on the content of rehabilitation programmes, counselling and support, and the family; the subject of occupational rehabilitation will follow a fortnight later.

Addresses will be listed at the end of the next article.

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Paediatrics Among Ethnic Minorities

Afro-Caribbean and African families

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West Indian families

The term Afro-Caribbean is now commonly used to indicate people from the West Indies who are of African origin. The population of the West Indies, however, includes many other races, of which those of Indian origin are the most numerous; but most families in Britain from the West Indies are of African origin.

Afro-Caribbeans and Africans have in common three important genetically determined conditions: sickle cell disease, haemoglobin C (or more commonly the combined condition Hb SC disease), and glucose 6 phosphate dehydrogenase (G6PD) deficiency. Their family structures and social problems are, however, quite different.

Immigration from the West Indies occurred mainly during the 1950s and 1960s owing to a combination of economic depression in the Caribbean and vacancies in lower paid jobs in Britain. About 60% of the immigrants came from Jamaica, the remainder from Trinidad, Barbados, and the smaller islands. The main areas of settlement were London, Manchester, Leeds, Nottingham, Bristol, Northampton, and Reading.^{1,2} In Reading most families came from Barbados,² while High Wycombe has a mainly Vincentian settlement.² In some cases the younger children remained at home for months or years before joining their parents in Britain. Many families retain strong ties with their homeland, and the older people regard themselves primarily as Jamaicans, Barbadians, etc, whereas those born in Britain consider themselves to be British but are conscious of their roots in the West Indies. The question "Where do you come from?" should be rephrased as, "Where does your family come from?"

SOCIAL STRUCTURE AND FAMILY LIFE

Traditionally, Afro-Caribbean society is matriarchal, with the father playing an inconspicuous part. Children are looked after by

the women of the extended family. When this tradition was brought to Britain several difficulties arose. Unmarried mothers had to work and, in the absence of other female members of the family, were forced to send their infants and preschool children to baby minders, who were often unregistered and gave the children little stimulation or affection. On starting school the children suffered disadvantages

FIG 1—Blood film of patient with sickle cell disease (by courtesy of Dr J C Sharp, Department of Haematology, King's College Hospital, London).

in language, and, later, in verbal and non-verbal reasoning and reading skills³; these disadvantages tended to persist throughout their school career and afterwards, when they started to look for jobs. Similar problems arose with the children of couples who, out of economic necessity, were both working. The present generation of Afro-Caribbean children entering primary school, however, have no language problems if they have attended a nursery school and are also more likely to have a stable home and to be looked after by their parents in the preschool years; their progress in primary school is now indistinguishable from that of other groups.