Contemporary Themes

Planning services for the mentally handicapped: a look at Sweden

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"The modern hospital does credit to latter day civilisation. Physical restraint is no longer practised. Neat dormitories, cosy single rooms, and sitting and dining rooms please the eye. In place of bare walls and floors and curtainless windows are pictures, plants, rugs, birds, curtains and, in many asylums, even the barred windows have been abolished."[1] This quotation from the *Encyclopaedia Britannica* of 1911 is part of an article on the mentally ill and mentally handicapped, which ends with the sentence, "But the ideal system is that of the psychopathic hospital and the colony for the insane."

Objectives in present-day care

While we are still using the buildings conceived in this period, no longer are they seen as a credit to our civilisation. Today the main goal for the care of all the mentally retarded is "normalisation," which obviously includes social contact with other people.[2] They should live in their own room, and in a small group, in a bisexual world, eating in a small group as a family with food and drink on the table. They should go out to work and be paid for their activities, being trained systematically to handle money by themselves. They should be able to choose between different ways of spending their free time, and their pursuits should be individually designed and vary according to the time of the year. As they grow up their environment should change, and retarded young people should be given the opportunity to detach themselves from their parents. This philosophy has relevance for new buildings and the organisation of existing services, which have been identified as follows[3]: (*a*) that they should be based on the principle of the small group of not more than 10 people (preferably four to eight, but more recently a maximum of six rather than 10 is recommended) living and eating together; (*b*) that the physical standard of the institution should reduce collective facilities to a minimum (such as toilets, basins and showers, and bedrooms); (*c*) that the institution should be situated within a community and not larger than will allow those living there to be assimilated into the local community; (*d*) that social contact should be freely developed in both directions; (*e*) that those living there should be offered alternative accommodation at weekends and holiday times; and (*f*) that the institution should consistently work in co-operation with relatives and the retarded persons themselves.

The principle of the small group is also important because of the sense of security which it gives to individuals.[4] The most modest objective for a group of retarded people living together is to avoid disturbing one another. The most ambitious objective is the formation of personal confidence, which enhances emotional and social performance. The small group is important because the number of alternative relationships within a group increases enormously with the size of the group. The number of alternative relationships in a group of three, for instance, is six: the corresponding figures for groups of four, five, six, seven, and eight are 25, 90, 301, 966, and 2059.

For the development of normal children the child needs to establish a close relationship with one individual, usually its mother, before it can cope with progressively larger groups, which enrich its experience. Failure to establish satisfactory links result in disturbed behaviour, in which the child fails to make the best use of its inherent talents. Similarly, with the mentally handicapped, disturbed behaviour will occur if they are placed in too large a group, because they will be unable to manage the large number of different relationships. The group is sometimes likened to a family and includes staff in close contact with the handicapped, so if there are too many staff, problems will arise. Continuity of these relationships over a period of time, usually years, is also important.[5] This continuity may be difficult to achieve if staff turnover is high.

Care in Sweden

How the mentally handicapped are cared for in Sweden is summarised in the table. Those mentally handicapped adults who can do so are encouraged to live in flats in ones and twos. A central flat, with perhaps two residents who are visited regularly by a social worker, is the focal point for eight to 10 handicapped people who live in the vicinity. Children and young adults live with their parents if possible. Staffed group homes, for slightly more dependent mentally handicapped people, are usually bungalows or ground-floor flats built at the same time as the estate and looking identical to other buildings. Ideally they are designed by an architect whose work is mainly with houses rather than institutions. Organisationally, group homes for children resemble foster homes, with perhaps a housemother in charge of four or five handicapped children and a husband who went out to work. The handicapped all go to education centres. The housemother has help for 23 hours a week and treats her four to five charges as family, washing their clothes and sheets and keeping the house clean. She also has her own budget. Ideally, each patient should have their own bedroom. The system works well with the mildly handicapped. It is important that the staff are properly trained and supported by the

Placing of the mentally handicapped in Sweden

	1970		1980	
	No	%	No	%
Children and young adults:				
Parental home	5343	19	8717	24
Foster home (children only)	329	1·2	737	2
Boarding home*	2630	9·2	1871	5·1
Residential home	2920	10·3	1365†	3·7
Adults:				
Parental home	6048	20·8	7011	18·8
Own residence	607	2·2	3983	11
Group home‡	489	1·7	3188	8·8
Residential home§	10 342	35·6	9594	26·3
Total	28 708	100	36 466‖	100

*Caters for 4-5 pupils and is integrated into society.
†Includes 85 in special hospitals. (Only 85 children were <7 years old.)
‡Caters for seven people in flats or separate houses.
§Each home caters for about 165 people. (In 1970 and 1980, 1631 and 670 respectively were in special hospitals.)
‖0·44% of the total population. (All mentally retarded are registered and the figure has been stable for the last five years.)

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district team. The 1981 budget for this home, for five children aged 15-21 years, was Kr 467 000 (£46 700), of which staff costs were Kr 235 000, which included the housemother, some hours for her husband, help for 23 hours a week, and cover for their annual leave. A central part of the philosophy is that the staff should help the patient spend his money by going with him to buy clothes or furniture for his room. The costs exclude day care but include transport, as no special transport is provided. In a group home for three severely retarded children as well as one in a wheelchair with no speech there were five whole-time equivalent staff (1·5 men and 3·5 women), who had created a pleasantly relaxed family group. There were two toilets, one specially adapted for the severely spastic child. This was a happy and pleasant home and the neighbours and friends often called to visit and chat.

The problems seem to start in the group homes for severely handicapped adults. In one home with seven places, one patient was in an acute hospital with a pyrexia of unknown origin, one, an old man, was asleep, and one younger man was walking rapidly around in an agitated manner; the others were at various day centres. The total staff was 15 (whole-time equivalents) including those on night duty. Because of incontinence the sheets were sent to an outside laundry. There was a special washing area for the handicapped woman who could not use a standard shower. The staff also supervised 10 other less severely mentally handicapped adults who were living on their own. There was little trouble from or contact with the neighbours, and one of the staff thought the patients would have had more freedom of movement in the larger residential homes where they could roam the grounds without disturbing neighbours.

A larger unit for 50 adults was situated on an island near Gothenburg which has a population of 2000. The original fabric had been rebuilt in 1979 and a day centre was nearing completion. The reason for rebuilding on this island, which goes against the general philosophy of integrating services for the mentally handicapped so they are an inconspicuous part of a wider community, was mainly because suitable staff were available and alternative employment would have presented major problems. There were nine units of five or six people, each with its own kitchen area where the staff cooked for the residents except during weekdays when the day centre was open and provided the midday meal. Eight of the units were in pairs with a communicating door for night cover. The staff also bought what they required from the neighbouring shops, including food, clothes, and furniture, taking one or two residents with them when they went shopping. Some had cultivated small garden areas around the home and grew gooseberries and wineberries. Staff turnover had fallen since the new smaller units had been introduced, and it was evident that many patients would respond to the sort of regimen where they were treated in small groups by a few staff who cooked, washed, and cared for them as a mother would do for a child.

For these moderately severely handicapped patients there seemed to be little advantage in siting them in group homes in the community. What matters is whom they live with rather than who their neighbours are.

Kallered (near Gothenburg) is a large site used for the mentally handicapped since the turn of the century, with 288 handicapped residents in 1980. One block, built in the 1960s, had been divided into four groups of eight; and here again the behaviour of the patients had improved considerably compared with another unit housing 32 similar patients which had not been divided. The most severely handicapped were in a ward of 18, of whom 12 were on holiday when I visited. The remaining six were severely handicapped; many were tube-fed and needed piped oxygen and suction. Even here, great care had been taken to provide pictures and mascots on the walls, although the floors had to be clear for nursing the patients.

At Noorkoping a residential home built in 1963 for 173 patients, including 50 children, now has 78 bedrooms (for 84 adult patients). A unit like this was needed to take patients who could not cope in small group homes, especially those with psychiatric disorders. The residents were housed in small groups of six or seven. Main meals were provided from the central kitchen, many patients being spoonfed by staff in the dining rooms in each unit. At night a member of staff could cover four units but it was usual to have one for each pair of units. There were 137 (whole-time equivalent) staff, and the budget in 1981 for 84 patients was £1·856 million (Kr 18·56 million).

Prevelance

In the Gothenburg area (population 700 000) 0·4% of the population are known to be mentally handicapped.[6] The register of the mentally handicapped for the Borough of Lambeth (Greater London) has identified 947 mentally handicapped children and adults for whom the borough and the relevant health authorities are responsible. With a population of 256 000, this is equivalent to 0·37% of the population and compares with the figures for the Borough of Camberwell.[7] The higher figures for Sweden could indicate a higher incidence. For example, in rural communities with much intermarriage, the rates are high.[3] In 1973, the 25 Swedish counties had rates varying from 0·7% to 0·32%. The rates in the cities are similar to those in Britain. Most of the handicapped cared for in the unified Swedish system, or in Britain by the social services and the health authorities, do not require the facilities being planned by health authorities. Thus if the total prevalence is 0·37%,[7] the number of adults who require facilities provided by the health authorities is only 0·055%. This small group of severely handicapped adults does have special problems and not all mentally handicapped adults can be managed in small community homes. Total care in small groups is important. Furthermore, care in the community should also be emphasised, although large numbers of the mentally handicapped will not benefit and would be better cared for in larger communities specialising in the needs of the handicapped.

Day care

Day care in Sweden is similar to that in Britain except that the centres cater on average for 26 patients (the largest are for 60 people), but Sweden is twice the size of Britain with a population of only 8½ million. One of the special features is that the handicapped spend one day in their home for home training with the staff and are encouraged to go out to lunch in local restaurants, initially with staff and later in groups on their own. In the larger residential homes, some of the residents go to the day centres off site and some people from outside come to the day hospital for physiotherapy.

Staff training

The mental hospital nurses formed one core and those that cared for the residents in the community needed a short course of seven days over a period of one or two months to discuss management and budgets. Other staff received a year's training mainly in service but with emphasis on group dynamics, particularly the caring role, which seemed easier for the women and younger men than for the older men. Staff who had no mental hospital background had difficulty in managing incontinent patients and drugs. In Stockholm the staff were dissatisfied with their training; too few were trained and the turnover in small homes was too great,[8] which are familiar problems to us in Britain. About 55% of all nursing staff at nursing homes and specialised hospitals in Sweden were untrained for their duties. This echoes the problems in Britain, which the Jay report has not resolved.[9] It is certainly more difficult to train staff in small units, but equally many large institutions fail to pay sufficient attention to training.

The items in training in Sweden were traditional, such as handling incontinent patients and medicines. An understanding of group dynamics, especially the problems of stress within the small groups, included the use of drama to show how the reactions of patients or staff vary with the manner in which they are approached either verbally or non-verbally.

Community teams

Community teams are fundamental to any community based services for the mentally handicapped. In Stockholm, there were 16 teams for a population of 1·5 million, and this compares with two teams for a district of a quarter of a million people, one team for children and one for adults, in Britain. The composition of these teams varies. Each should have a doctor (part-time), a nurse, a psychologist, and a social worker. The duties of the team are to support the handicapped, their relatives, and the staff who look after them. The need to support the staff is an essential element and should include training programmes for staff as well as patients. The success of any local service in retaining good staff and ensuring appropriate placements depends to a large extent on the calibre of the members of the district team. They clearly need contact with hospitals serving their catchment area, but this should be a small part of their work.

Conclusions

My conclusion is that for the severely mentally handicapped a residential complex of about 70 places on one site is the best solution, provided the residents are in small groups of six or eight so that each will have their own home unit where they eat most of their meals and a small staff dedicated to that unit as far as possible. Most units will need to be in pairs, so that night staff can be shared when possible. There should be sufficient single rooms. Although I am not convinced that all patients need single rooms, disturbed behaviour is likely to be much less if each mobile adult has his own personal belongings, including furniture he has bought and paid for himself and in which he can take a pride. These considerations apply less to the very small number of the most severely handicapped who are unable to move without assistance and require virtually total care. Small units in the community have an important complementary role, but few of the most severely handicapped adults will be able to integrate with their neighbours in the community and their isolation is therefore much greater than if they are part of a larger complex.

Day activities are essential, both on site and off site. Thus the day activity complex on site should be available to the mentally handicapped living elsewhere who would benefit from these facilities, and, similarly, those residents who would benefit by attending day centres in the community should be able to do so. The whole emphasis should be on small homely residences with as wide a variety of activities as possible on the campus and outside it.

I thank the many people who have helped with this paper and especially those I met in Sweden who gave so freely of their time. While the conclusions are my own, they are based on discussions with a large number of colleagues to whom I am grateful, especially Dr Karl Grunewald, who organised my visit. I also thank the special trustees of King's College Hospital for a grant to cover my expenses.

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Letter from . . . Zambia

Land of scarcity

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Some 20 miles from Chipata the road to Msoro leaves the Great East Road and turns north. Half a mile (0·8 km) further on the tar gives place to dirt, and from then on the way runs across the Zambian plateau; past beobabs and mangos, through the "fly gate" where a man solemnly circumambulates the vehicle tapping with a butterfly net to trap any travelling tsetses, down a lush little valley, and finally to the river. Traces of a bridge remain, but that was once upon a time. Now packs are hoisted on to the head, I grasp my skirt and lift it high, and we wade through the opaque, tepid water. For us, doctor, driver, and a few returning patients, there is another Land Rover to carry us to the village, with its vast desolate church, decaying mission houses, and rural health centre.

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Rural health centres

The rural health centres, together with their satellite clinics, form the substructure of the Zambian health service. In this sparsely populated part of the country where mechanical transport of any kind is scarce and expensive, and horses, because of the tsetse, unknown, it is the only feasible system. The centres are staffed mostly by medical assistants, men with a fairly high level of education who then undergo a three-year training, after which they work under supervision for a time before being appointed to their own domain. As government employees they are likely to be moved from time to time, but most stay in the area for some years and therefore get to know it well. Like all graduates they vary in quality and the interest they bring to the job. Their besetting sins are a tendency to regard any criticism, however mild, as evidence of racism and polypharmacy. Doctors visit them regularly, and in the intervals patients are referred direct, the accompanying letters brightening many a busy outpatient clinic. "The diarrhoea has been defeated, but the condition continues to lower." Msoro is in the capable hands of Mr Jackson Banda, a quietly spoken man of middle age. In some respects my ward rounds and outpatient sessions were redundant, for those needing further treatment had already been selected. So we returned with a panopthalmitis (the result of a