

# **A MENTAL HANDICAP SERVICE IN ADVERSITY: THE RESPONSE OF TWO GROUPS OF RELATIVES TO A PERIOD OF INDUSTRIAL ACTION**

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## **INTRODUCTION**

In 1982 a period of industrial action by health service staff necessitated a change in the planned functioning of many hospitals. This occurrence provided an opportunity to evaluate certain areas of the health service in a quite unusual way. That is, by monitoring the consequences of withdrawal of particular services and considering whether these consequences reflect the basic assumptions on which the provision of these services was originally made.

It may, for example, be found that it is not the normal recipient of a service that bears the brunt of its suspension or that those parts of the service requiring the greatest investment of resources may not be the parts which, when absent, create the greatest hardship. Also, by noting to whom patients in such circumstances turn for help, some insight may be gained into the patients view of the utility of the various professionals involved in the service. It is also of interest to note the nature and adequacy of any alternatives the patient may find to existing services. Clearly, this kind of evaluation may have implications for the future development of services.

Mental handicap hospitals seem to have been among the most disrupted during the period of industrial action and it is perhaps in the provision of services to the handicapped that most can be learnt from its effects. The care of the mentally handicapped is an area of change and expansion and it would seem important that, in a speciality whose clientele are notoriously slow to complain, a self critical attitude is adopted and that no opportunity is missed to examine the nature of the services provided.

## **PATIENTS AND METHODS**

Two groups of mentally handicapped patients, normally living at home with relatives and varying in age from 5-63 were considered —

*Group A* patients were those patients for whom the industrial action had meant the cancellation of a booked period of inpatient holiday care. Towards the end of the period of industrial action the relatives of *Group A* patients were sent a questionnaire designed to assess —

- 1) Any action taken by the relatives to try and bring about the holiday admission as planned and who, if anyone, had assisted them in this (e.g. General Practitioner, Social Worker, etc.)
- 2) The consequences if admission did not occur, what their feelings were, what problems arose, what alternatives they found available and whether they complained (e.g. to Health Board, M.P., etc.)

*Group B* patients were those patients who had no holiday admission booked and for whom emergency admission was requested during the period of industrial action. At the beginning of the dispute it had been agreed that all these patients would be visited at home by a doctor and nurse from the hospital and only if they found the home situation to be critical, would admission be possible.

Towards the end of the industrial action, the relatives of *Group B* patients were sent a questionnaire designed to assess —

- 1) For what reason admission was requested.

- 2) How the request was made.
- 3) The relatives views on the usefulness of the assessment visit.
- 4) The consequences if admission did not occur, what their feelings were, who, if anyone, they found supportive, what alternatives they found available and whether they complained.

## RESULTS

### Group A Patients

Over the period of industrial action, 41 holiday admissions were scheduled to have occurred and 39 of these patients lived at home with relatives. On the commencement of industrial action letters were sent to all families cancelling this holiday and explaining why.

Of 39 questionnaires sent, 33 were returned. Admission had occurred as promised in five cases. Of these five cases relatives had, on receipt of the cancellation letter, in two cases contacted the hospital themselves to ask that the decision be reconsidered, in two cases asked their general practitioner and a social worker to intervene on their behalf and in one case asked their general practitioner and community nurse to intervene. In these five cases beginning of the dispute it had been agreed that all these patients would be visited at home situation to be critical.

In 28 cases admission did not occur as promised. In 11 of these cases, on receipt of the cancellation letter, relatives had taken action to try and bring about admission as planned. In five cases the relatives contacted the hospital directly, in three cases they asked their G.P. to intervene and in three cases they asked a social worker to intervene. These 11 cases were visited by a hospital doctor and nurse and admission was refused.

In 17 of the 28 cases where admission did not occur, no action had been taken by relatives to try and bring about admission as planned.

Of the 28 cases not admitted, in 12 cases the relatives described feeling desperate and in five cases disillusioned and angry. In seven cases booked family holidays had to be cancelled and in 18 cases relatives felt they had suffered more than the handicapped person they cared for. No alternative source of help was found in 16 cases, while in five cases relatives looked after the handicapped individual for a period and in two cases, a paid carer was employed. Adult Training Centres provided short holidays in four cases and unpaid volunteer carers were involved in one case. None of these 28 cases complained.

### Group B Patients

Over the period of the industrial action 26 requests for emergency admission were made and 21 of these patients lived at home with relatives.

Of 21 questionnaires sent, 16 were returned. The main problem leading to the request for emergency admission and the number of cases actually admitted in each group is summarised in Table 1.

**Table 1**

<i>Main problem</i>	<i>Number of cases</i>	<i>Numbers admitted</i>
Physical illness in patient	2	2
Psychiatric illness in patient	2	2
Behaviour problem in patient	7	4
Emotional/Psychiatric problems in carer	5	3
<b>TOTALS</b>	<b>16</b>	<b>11</b>

Who approached the hospital with the request for emergency admission is summarised in Table II.

**Table II**

<i>Person approaching hospital</i>	<i>Number of cases</i>	<i>Numbers admitted</i>
Relative	4	3
G.P. alone	2	1
G.P. and social orker	4	3
G.P. and community nurse	2	1
Social worker alone	3	2
Psychologist alone	1	1
<b>TOTALS</b>	<b>16</b>	<b>11</b>

Not surprisingly, in all 11 cases where the patient was admitted, the relatives felt the assessment visit paid by the hospital doctor and nurse to be helpful. In three of the five cases where admission not occur, the visit was still felt to be helpful.

Of those five cases where admission did not occur, relatives described feeling desperate in two cases and disillusioned in one case. In three cases relatives reported finding community nurses of great support and in one case a social worker was found supportive, having arranged a short period of admission to a hostel. In only one case did relatives complain and this was to their Member of Parliament. This relative reported no support from either Community Nurse or Social Worker.

#### DISCUSSION

Clearly the cancellation of booked holiday admissions caused relatives considerable suffering, leaving many feeling desperate, disillusioned and angry. The majority were able to find no suitable alternative, particularly those without an extended family. Relatives generally seemed to regard being able to look forward to a planned holiday as crucial and more valuable than support of other types.

It seems surprising that in only 16 out of 33 cases did the relatives of group A patients take action to try to bring about the holiday admission as planned and in only six of these cases did they involve their G.P. Of these six cases, three were admitted, whereas of the ten cases where the hospital was approached without the involvement of the G.P., only two were admitted. Probably the more critical the home situation, the more likely the G.P. was to be involved and the more likely the assessing hospital doctor and nurse were to regard it as necessitating admission. However some explanation is required why relatives in 27 out of 33 cases either accepted the loss of the holiday or did not involve their G.P. in approaching the hospital with a request that the decision be reconsidered. This explanation must also account for the fact that even in making a request for emergency admission relatives of Group B patients, involved their G.P.s in only 8 out of 16 cases, 5 of which were admitted.

A clue to the answer may lie in the finding that as far as requests for emergency admissions were concerned, non involvement of the G.P. was not associated with a decreased likelihood of admission, 6 out of 8 such cases were admitted. This suggests that relatives encountering acute difficulties are tending to take these difficulties to the hospital based doctors, community nurses and social workers rather than involve their G.P.s. This may mean that relatives are beginning to view Mental Handicap hospitals as the primary source of health care for their retarded dependents in the community and this seems to be in keeping

with the move of Mental Handicap hospitals away from purely custodial considerations and towards their establishment as community resource centres. However, this "short circuiting" of G.P.s may be at variance with the principles of normalisation which suggest that the mentally handicapped be dealt with as far as possible, in the same way as are those without handicap.

The finding that in none of the 28 cases in which holiday admission was refused and in only one of the five cases in which emergency admission was refused, did the relatives complain, although not unexpected, is a little regrettable. One of the priorities of the professionals involved in the care of the handicapped must be to increase the advocacy of the relatives caring for them. It is salutary to note that the one relative who did complain (to her Member of Parliament) was immediately rewarded with an emergency place at an Adult Training Centre.

### **SUMMARY**

The consequences of a change in the admitting policy of a mental handicap hospital are assessed by means of a questionnaire study of relatives.

It is shown that relatives view planned holiday admissions as of crucial importance to their continued coping, that General Practitioners are being to some extent bypassed by relatives in their dealings with Mental Handicap hospitals and that relatives are remarkably uncomplaining as to the nature of the service they receive.

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