

Symposium on 'The Way into the Community'

I. A REVIEW OF THE GOVERNMENT GUIDELINE FOR RESIDENTIAL PROVISION FOR MENTALLY HANDICAPPED PEOPLE IN SCOTLAND

S. MONTGOMERY, P. ASHE, P. HAMBLETON, T. McNEELY
and A. ROBERTSON

Social Services Research Group, Scotland

INTRODUCTION

Service guidelines are widely used in planning and investment decisions by both local and central government and by health authorities. In the field of mental handicap, guidelines have achieved considerable importance: in negotiations both within and between agencies the degree of priority allocated to the provision of additional resources often depends crucially on how the local area's progress towards the guideline targets compares with that of other, particularly neighbouring, areas. Paradoxically, however, the planners' heavy reliance on guidelines is matched by a frank recognition that they are in many cases very crude indicators, derived merely from current levels of provision and patterns of development.

The pragmatic decision to aim at targets not personally endorsed is understandable, for with most client groups, and certainly in the case of mentally handicapped people, existing provision falls far short of the guideline targets; consequently it may seem reasonable to postpone any critical examination of the guidelines themselves until their attainment (and the resultant danger of curtailment of growth still desired) becomes more imminent. It is our view, however, that such a response is short-sighted and does harm to the prospect of an adequate policy of community care.

This position rests upon our analysis of the current Scottish guideline for residential places in the community.⁽¹⁾ In the present paper we shall argue that this guideline, though ostensibly based on a policy of community care, in fact reflects an extremely limited formulation of that policy. We feel that the interests of mentally handicapped people will best be served if this short-coming is highlighted and discussed now. To delay criticism of the target until it is matched by resources would be to collude with the consistent failure by government to appreciate the scale of the task of community care.

THE EXISTING GUIDELINE

The current Scottish guidelines for residential and other resources were set out in 1979 by the Peters Sub-committee in its report entitled *A Better Life* (H.M.S.O., 1979). Guidelines operative prior to that date had been outlined in a joint memorandum from the Scottish Home and Health Department and the Scottish Education Department, which had recommended a total provision of residential places at the rate of 1.6 per 1,000 population, to be distributed as 1.2 hospital beds and 0.43 residential places in the community. Peters increased the overall figure to 1.8 places per 1,000 population, raising the rate for community places to 0.6, while leaving the hospital provision at 1.2. These new recommendations were based firstly on an estimate of prevalence of mental handicap, and secondly on a particular set of assumptions about patterns of need. We shall consider these two aspects in turn.

(1) The present paper reports part of a wider project being undertaken by Social Services Research Group (Scotland) at the request of the Association of Directors of Social Work. Reviews of guidelines for other client groupings — e.g. elderly people — are at the planning stage.

Prevalence

On the basis of epidemiological studies undertaken in Scotland up to 1978 (Richardson, 1975, Innes *et al.*, 1978) the Peters Report (1979) estimated that the numbers of mentally handicapped people in need of services in 1981 and 1986 would be as shown in Table I.

Table I

Expected Numbers of Mentally Handicapped People (Peters Report, H.M.S.O. 1979)

	<i>Moderate and Severe</i>			<i>Mild</i>		
	<i>rate per 1,000</i>	<i>1981</i>	<i>numbers 1986</i>	<i>rate per 1,000</i>	<i>1981</i>	<i>numbers 1986</i>
Pre-school	3.0	990	1,200	—	—	—
School-age	3.6	3,180	2,780	9.3	8,210	7,170
Adult	3.0	11,840	12,030	2.1	8,290	8,420
TOTALS		16,010	16,010		16,500	15,590

We know of no evidence indicating that these estimates of overall prevalence need revision. Only one survey appears to have been carried out in Scotland since the publication of the Peters report (H.M.S.O. 1979). That survey examined mentally handicapped children up to (and including) age 16 in Moray District, and showed an administrative prevalence for all grades of 5.32 per 1,000 (Grampian Regional Council Social Work Department, 1982). Considered in the context of the decrease in school-age prevalence predicted in the table above, this rate is broadly in accord with Innes *et al's* finding (for the old Moray County) of a rate of 6.4 per 1,000. In the absence of any other information there is no reason to question Peters' figures, to which we shall return later.

Assumptions about need

Peters' recommendations are explicitly based on the assumption (stated in para. 2.15 of the report) that "those *presently* in residential care of various kinds provide the best estimate of the current level of need" (emphasis added). Having made this assumption it followed necessarily that the Peters Sub-committee could not propose any additions to the overall total existing provision, but would be limited to suggesting changes in the relative emphasis upon hospital and community resources. The first step in setting the guideline was therefore to establish the "total residence rate" of mentally handicapped people. This was achieved by adding to the number of mentally handicapped patients in subnormality and psychiatric hospitals, the numbers on hospital waiting lists and in local authority and voluntary residential provision in the community. Table II reproduces Peters' estimates, which relate to 1975, and allows comparison with 1980 (the most recent complete figures).

Table II

Nos. of Mentally Handicapped People in Res. Accommodation

		1975		1980	
In subnormality hosps.	(1)	7,102	1.36	6,668	1.29
In psychiatric hosps.	(1)	1,091	0.21	903	0.18
In L.A. and vol. homes	(2)	776	0.15	1,093	0.21
On hosp. waiting list	(1)	500	0.10	450	0.09
TOTAL		9,469	1.82	9,114	1.77

Notes

- (1) Source for 1980 figures: H.M.S.O. (1980)
 (2) Source for 1980 figures: S.W.S.G. (1981)

Peters' next step was to suggest that a proportion of those in hospital were capable of discharge, and that local authority accommodation should be expanded to cater for them. That proportion was set at 25%, on the basis of the Sub-committee's review of some contemporary research on the perceived needs of in-patients. The figure for existing hospital provision was consequently reduced by one quarter, and the balance added to the rate for community provision. When the figures were rounded, the guideline rates of 1.2 and 0.6 resulted for hospital and community respectively.

**THE EXISTING GUIDELINE AS A LIMITED OPTION, AND A SUGGESTION FOR
 A REVISED LIMITED OPTION**

It was pointed out above that Peters' guideline was based on, and could not exceed, the contemporary total level of hospital and community places. Beyond the inclusion in the calculations of those presently on hospital waiting lists, the possibility is not considered that residential provision might be needed for those presently living in *non-institutionalised* settings in the community (for example with their families). The proposed extra community places are intended by Peters to cater entirely for dischargeable hospital patients.

We suggest that on account of its exclusion of mentally handicapped people living in non-institutionalised settings, Peters' target should be regarded as a limited option — reflecting a limited formulation of the policy of community care. We also suggest that even within this limited formulation the target should be revised: there is strong evidence that the Sub-committee was too cautious in fixing the community rate at 0.6 places per 1,000.

To begin with, it is worth pointing out that the claim that 25% of in-patients could be discharged was based on only two sources. One of these is not referenced by Peters, making it impossible to evaluate independently. The other source is referenced (Fraser *et al.*, 1977) but on examination it can be seen to be largely a broad statement of the aims and objectives of the hospital in which its authors work. Given the authors' intentions, it is understandable that the only coverage of the patients' readiness for discharge is contained in one paragraph of the section contributed by the hospital's clinical psychologist, where it is not made clear, for example, whether the presented figures relate to all the hospital's patients or merely to those so far assessed. It seems to us that this is a somewhat unsatisfactory empirical basis on which to construct a guideline.

Furthermore, and more importantly, it is clear that the conclusions of the two studies reviewed by Peters are among the most cautious to have emerged in the last fifteen years or so in Britain. As early as 1967 Leck, *et al.* (1967), in an English study, reckoned that about half of their in-patient population did not require primarily specialised hospital residence. In 1971 Browne, *et al.* estimated that 53% of patients in subnormality hospitals in the Birmingham area did not need hospital care, and in the same year Williams (1971) set the figure for Berkshire at: "a large proportion — between a third to a half — of patients in subnormality hospitals."

The team led by Browne and Gunzburg repeated their survey after a lapse of some eight years. Their hypothesis — that the most capable patients would have been discharged in the interim and that consequently those remaining would be more difficult to discharge — was not borne out. Rather, using the same criteria as in the 1971 study, the authors found that 58% of in-patients were now (in 1979) considered by their consultant to be suitable for discharge. They concluded that the consultants' experience of successful community placements is leading them to reconsider their estimations of patients' potential: it is being realised that, given adequate support, more and more severe cases can be accommodated outside hospital (Browne *et al.*, 1979).

The studies just reviewed suggest that the number of patients currently in hospital could be reduced by 50%. We therefore recommend that even if it is thought desirable to remain within the limited formulation of community care which Peters proposes, the guideline should be revised to incorporate this higher percentage. Arithmetically this revision would take place as follows. The "limited option" assumption used by Peters implies that community places should be increased by just enough to cater for the dischargeable hospital group. Summing the 1980 rates (presented in Table II above) for psychiatric and subnormality hospitals and waiting lists gives a rate of 1.56. Fifty percent of this equals 0.78, and within the limited option this becomes the revised hospital rate. Adding the remaining 0.78 to the 1980 level of community places (0.21) yields a rate of 0.99. Rounding up slightly, the revised limited option guidelines would become:

Hospital places	0.8 per 1,000
Community places	1.0 per 1,000

(Under "community places" we include all forms of supported accommodation — hostels, group homes, etc.)

TOWARDS A WIDER VIEW OF COMMUNITY CARE: A SUGGESTION FOR A "WIDER OPTION" GUIDELINE

Peters' limited perspective on the development of residential facilities does not take sufficient account of the fact that considerable need for such resources exists among mentally handicapped people presently living with family or other relatives. As we have just seen, this group was largely excluded from the Sub-committee's calculations; and this is surprising, for the Peters Report acknowledges (para. 2.19) that:

"Many of the hostel places provided in recent years have been taken up by persons from the community rather than by transfer of patients from hospital . . ."

Confirmation has come from other sources that fulfilment of the residential needs of those meantime living "informally" in the community cannot be regarded as something to be postponed until we have sorted out the hospitalised group. An investigation carried out by Warwickshire County Council Social Services Department (1977) found that over half those admitted to hostels for adults during a five-year period had come straight from their family home. Some observers maintain that most admissions to residential facilities are of this type; indeed, Tyne (1981) has gone so far as to say:

“There is little evidence to suggest that the reduction in numbers of ‘beds’ in mental handicap hospitals is in any way related to active discharge programmes. Rather it is almost wholly accounted for by the high death-rates among an increasingly elderly institutional population. There is a prevalent belief that people are being moved from institutional care to community care. This belief is almost totally unsupported by research evidence.”

Although the need for facilities for those meantime living with their families can clearly be seen, it can less easily be quantified. As far as we are aware no study has directly addressed the topic, so indirect evidence must therefore be sought. The most important factor is the age of the parents of mentally handicapped people — highlighted some years ago by Bayley (1973) who pointed to the fear among many parents over what will happen to their child when, through death or ill-health, they themselves can no longer provide care. This factor has been examined in recent studies in Coventry (Coventry Social Services Department, 1980) and in Central Region (Central Regional Council Social Work Department, 1982). The Coventry study found that 47% of those living with their parents or relatives had a “main caring person” aged 50 or more (in 20% of cases the main carer was aged 60 or more). From Central’s report it is clear that 67% of Adult Training Centre attenders in the Region had parents or relatives aged 50 or more; in 39% of instances they were aged 60 or over. In many cases, moreover, the parent or relative was not only ageing but was single.

These figures suggest that over the next 20 years between a half and two-thirds of all mentally handicapped adults currently living with their parents or relatives will be potentially in need of alternative accommodation due to their ageing care-giver’s increasing difficulty in looking after them. In some cases the family will be able to be supported by increased domiciliary care, and in other cases the mentally handicapped person will be capable of finding alternative accommodation for himself. In many other instances, however, the family will not be able to manage, even with extra services, and the child — after many years of dependence on his parents — will not be able to cope with independent living. The proportion needing some form of supported accommodation is uncertain, but we suggest that it is unlikely to be less than half of those with parents or other caring relatives at present aged over 50. Roughly, this comes out at 25% of all those mentally handicapped adults living “informally” in the community.

We recommend that this group be taken into account in the establishment of guidelines based on a wider, and more appropriate, conception of community care. Arithmetically these guidelines would be derived as follows. The baseline figures would be those presented above in our “revised limited option”. To the revised community rate (1.0 per 1,000) would be added a rate equivalent to 25% of adults living in non-institutional settings — that is 0.8 per 1,000. (For those living in non-institutional settings subtract the present “total residence rate” of 1.8 per 1,000 (Table II) from the total adult prevalence of 5.1 per 1,000 (Table I). This leaves 3.3 per 1,000 — 25% of which equals 0.8 per 1,000). The resulting wider option guideline figures are therefore:

Hospital places	0.8 per 1,000
Community places	1.8 per 1,000

CONCLUSION

In this paper we have reviewed the present Scottish guideline for residential provision in the community, and we have recommended that it be discarded as inadequate even within the terms of the limited perception of community care on which it is based. We have calculated two alternative guidelines: one which remains within the limited framework used by Peters, the other based on a wider concept of care in the community. We suggest

that governmental acceptance of even the first of these would represent a considerable improvement on the present situation, but we urge strongly that the current guideline be brought into line with our second, wider option.

We fully appreciate the resource implications of our proposals.⁽¹⁾ The following table shows the different numbers of community residential places implied by Peters' and by our own guidelines. It also shows the dismally low level of existing (1981) provision, and expresses this as a percentage of the different targets.

Table III
Existing and Required Numbers of Community Places

		<i>No.</i>	<i>Existing as % of target</i>
Existing (SWSG), 1981		1,155	—
Peters	(0.6 per 1000)	3,090	37.4
Limited option	(1.0 per 1000)	5,150	22.4
Wider option	(1.8 per 1000)	9,269	12.5

We began this paper by arguing that to postpone criticism of the existing guidelines would be short-sighted. We end by re-emphasising the point. Pressure on government to release more resources for community care for mentally handicapped people must surely increase if it can be convincingly argued that existing residential places in the community represent not 37.4%, but only 12.5%, of what is needed.

(1) We also appreciate that the implications of our recommendations extend necessarily to the topic of day care. It is clear that increased provision of ATCs, sheltered employment etc., would be essential if, as we suggest, a large number of hospital patients were discharged. Our preliminary calculations indicate that the present target for ATCs of 150 places per 100,000 population would need to be raised to almost 250 to cater for a transfer of patients on the scale we recommend.

REFERENCES

- BAYLEY, M. (1973) *Mental Handicap and Community Care. A Study of Mentally Handicapped People in Sheffield*. Routledge and Kegan Paul. London.
- BROWNE, R. A., GUNZBURG, H. C., JOHNSTON HANNAH, L. G. W., MacCOLL, K., OLIVER, B., THOMAS, A. (1971) "The needs of patients in sub-normality hospitals if discharged to community care". *Brit. J. Ment. Subnormality*. Vol. 17, 32: 7-24.
- BROWNE, R. A., CANNING, W. C., GOULDEN, G., GUNZBURG, H. C. and VALSALAN, V. C. (1979) "A survey of adult patients in four hospitals for the mentally handicapped". *Brit. J. Ment. Subnormality*. Vol. 25, 48: 33-37.
- CENTRAL REGIONAL COUNCIL, SOCIAL WORK DEPARTMENT (1982) *Services to Mentally Handicapped People*.
- COVENTRY SOCIAL SERVICES DEPARTMENT (1980) "Mentally Handicapped People in Coventry", Clearing House for Local Authority Social Services Research, University of Birmingham, 1980, No. 7.
- FRASER, W., PRESHAW, C., SUTHERLAND, A. H., DICKENS, P. (1977) "The first eight years of a mental handicap service". *Health Bulletin*, March 1977, 66-70.
- GRAMPIAN REGIONAL COUNCIL, SOCIAL WORK DEPARTMENT (1982) *Mentally Handicapped Children in Moray District*.
- H.M.S.O. (1979) *A Better Life. Report on Services for the Mentally Handicapped in Scotland* (The Peters Report) S.H.H.D./S.E.D.
- H.M.S.O. (1980) *Scottish Health Statistics, 1980*.
- INNES, G., JOHNSTON, A. W. and MILLER, W. M. (eds.) (1978) *Mental Subnormality in North-East Scotland — a multidisciplinary study of total population*. Scottish Home and Health Department.
- LECK, I., GORDON, W. L. and McKEOWN, T. (1967) "Medical and social needs of patients in hospitals for the mentally subnormal". *Brit. J. Prev. Soc. Med.* Vol. 21, 3: 115-121.
- RICHARDSON, J. N. (1975) *Regional Patterns in the Education and Training of Severely Handicapped School Age Children in Scotland*. Scottish Society for the Mentally Handicapped.
- S.W.S.G. (Social Work Services Group) (1981) *Residential Accommodation for the Elderly and Certain Other Adults, Scotland 1980*.
- TYNE, A. (1981) "The impact of the normalisation principle on services for the mentally handicapped in the United Kingdom". Research Highlights, No. 2 (*Normalisation*). Aberdeen University.
- WARWICKSHIRE COUNTY COUNCIL, SOCIAL SERVICES DEPARTMENT (1977). "A Review of Services for the Mentally Handicapped in Warwickshire". Clearing House for Local Authority Social Services Research, University of Birmingham, 1977, No. 8.
- WILLIAMS, C. E. (1971) "A study of the patients in a group of mental subnormality hospitals" *Brit. J. Ment. Subnormality*. Vol. 17 32: 29-41.

Requests for reprints to S. Montgomery, Grampian Regional Council, Social Work Dept., Woodhill House, Ashgrove Rd. West, Aberdeen AB9 2LU.