

Correspondence

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CARE OF THE MENTALLY SUBNORMAL

DEAR SIR,

Kushlick has stressed the importance of using epidemiological data in the planning of services for the mentally subnormal (1, 2). On the basis of a comprehensive survey, sometimes referred to as the Wessex Project, he has suggested among other things that there is probably a large discrepancy between the observed (ascertained) and expected (actual) numbers of severely subnormal (SSN) children in a 'standard' general population of 100,000 (3); that many patients at present living in subnormality hospitals and other institutions do not require *continuous* medical and nursing care (4, 5) and could be cared for in 'substitute homes' or hostel accommodation (6); that the numbers and types of patients having maximum or minimum need of residential and nursing care can be identified (4, 6); that it is possible to plan realistically the nature and size (bed complement) of hostel accommodation for a 'standard' general population of 100,000, and that eventually these hostels will take in not only *all* the children who are at present in traditional institutions but also those who are on waiting lists for admission (1, 7). Investigations in other parts of Britain support the contention that many patients in institutions do not require continuous specialist care in hospital and could be cared for in hostels (8, 9). These are all relevant and important points.

We do not in any way question the view that the increasing amount of epidemiological information available to us should be applied to the planning of services for the mentally subnormal. We do not contest the evidence (discussed by Kushlick (1)) that small units are preferable to large institutions, particularly in the case of children. We agree that many patients in institutions at the present time do not need continuous specialist treatment and could very well be cared for in hostel accommodation. But we are concerned about the extent to which one can generalize the findings of the Wessex Project and apply them to other regions. The value of any investigation like this lies in the applicability of its findings to the region where it was carried out, and, more important, to other areas where such a

comprehensive survey is not possible for economic or other reasons. There is the danger that planners may be tempted to accept Kushlick's calculations without first checking whether the basic epidemiological information for their areas is comparable to his. Further, his use of 'standard' populations of 100,000 may give rise to the impression that his findings, presented in this form, have a general application to the country as a whole. Recent investigations in Northern Ireland have shown that the population of ascertained subnormals differs in some respects from that described by Kushlick. The purpose of this communication is to describe briefly what these differences are, how local epidemiological data affect the planning of provisions, and to stress the importance of obtaining such information. The data on which Kushlick's arguments are based comprise the prevalence rate of mental subnormality, the birth rate in the general population, the numbers of severely subnormal (SSN) and moderately subnormal (MSN) children and adults at present in institutions or living at home, and the classification of patients according to certain criteria of behaviour, physical handicap, self-help, etc. (4).

1. SEVERELY SUBNORMAL CHILDREN—EXPECTED AND OBSERVED NUMBERS

The most reliable prevalence rate is that of patients in the 15-19 age group (12). For the Wessex region it is about 3.6 per 1,000 of the general population (3); other investigations in England have yielded approximately the same figure (10, 11). But prevalence rates can differ markedly (13). The birth rate for England and Wales is about 16 per 1,000 (1, 3). With these figures it is possible to make crude estimates of the total number of children and the number of SSN children to be expected within given age ranges in a 'standard' population of 100,000. The numbers of expected SSN children can then be compared with the obtained or ascertained numbers. Kushlick calculated that only four of about 30 SSN children expected in the age range 0-4 were known to the Mental Health Department of the Local Health Authority. 'At least some' of the remaining 26 cases would be known to general practitioners,

paediatricians and health visitors and were probably not notified because of the inadequate services provided by the Mental Health Departments. Of the 66 SSN children expected in the age group 5-15, only 47 were known to the Mental Health Department. The remaining 19 were 'likely to be attending ordinary or special schools' (3). The inference is clear: not enough is known of the whereabouts of SSN children and some of them may be suffering as a result of this.

In Northern Ireland, where the responsibility for subnormal patients is vested in the Special Care Service (14), the prevalence rate of severe subnormality in the age range 15-19 for the whole province is 4.7 (15, 16), the urban rate is 4.2 and the birth rate (averaged over 12 years) is 22 per 1,000 of the general population. There are considerable intra-regional variations (17), and the prevalence rate of mongolism is higher than that reported elsewhere (18). We carried out an investigation in Belfast County Borough to determine how many SSN children could be expected in the age range 0-15, how many have been notified to the Special Care Service, and whether those not registered with the Service were officially known to other statutory bodies. Because of their availability, we examined the actual numbers of children in this age range rather than estimate them on the basis of the birth rate. Using the prevalence rate of 4.2 we found that approximately 115 SSN children could be expected per 100,000 of the urban population. Of these, 85 were known to the Special Care Service and 26 to the School Health Service. In other words, whereas Kushlick could account definitely for just over half the expected numbers in his survey, and 70 out of 96 if the 19 'missing' cases in the age group 5-15 could be assumed to be attending ordinary or special schools; in Northern Ireland we can account for all but about four SSN cases in a unit population of 100,000.

We conclude that (a) since there are marked differences in the epidemiology of subnormality between at least two regions within the United Kingdom, planners should make every effort to establish prevalence and other rates for their own areas and should not rely too much on estimates obtained elsewhere; (b) on the basis of locally obtained information, there appears to be a much better notification and registration system in Northern Ireland of SSN children than might be expected from the figures provided by Kushlick.

2. TYPE OF CARE FOR THE MENTALLY SUBNORMAL

Table I shows the numbers of SSN and MSN children and adults under institutional and community care in Wessex and Northern Ireland per 100,000

of the general population. The numbers for this province refer only to those registered with the Special Care Service. The SSN cases not yet notified by other statutory bodies are not included.

In the Wessex region there were approximately 20 children under hospital care and a further two

TABLE I

Numbers of ascertained SSN and MSN children and adults under institutional and non-institutional care in Wessex and Northern Ireland, per 100,000 of the General Population

	Wessex		Northern Ireland	
	Inst.	Not inst.	Inst.	Not inst.
Children SSN	18	30	22	62
MSN	2	9	1	6
Adults SSN	81	51	84	111
MSN	53	76	40	81

on the waiting list (4). Kushlick argues that 'if each population area of 100,000 people were to provide about 25 places for the residential care of all grades of subnormal children aged under 16 arising in the area, there would be no children in the existing hospitals for the subnormal nor on the waiting lists for admission' (1). The information obtained for Northern Ireland shows that there are about 23 children under residential care in a similar population area. There are five on the waiting lists for admission. It would seem, therefore, that a comparable residential unit would need about 30 beds to accommodate these children. A difference of five beds per residential unit between the two regions sounds paltry. But for Northern Ireland as a whole this would entail an extra 75 beds over and above the figures suggested by Kushlick.

But there is another very striking feature about the information provided in Table I. This concerns the differences between the regions in the proportions of children and adults under residential care. Over half of the SSN children in Wessex are in institutions. By contrast, only one-third of SSN children in Northern Ireland are under such care. Well over half the SSN adults in Wessex are under hospital care compared with less than half in this province. The fact that there are more cases on the waiting lists for admission to hospital in this province is not enough to account for these discrepancies. We tentatively suggest that there may be a difference between the two regions in the 'tolerance thresholds' of society, or of the families with subnormal children, towards the question of admission to hospital. A recent investigation in this province confirmed the

view (19) that the tolerance threshold of society, or of the affected families, towards this problem appeared to be related to the sex, age and grade of the subnormal (20). If, because of some change of society attitudes towards the subnormal, the proportions of cases under residential care in Northern Ireland were to approximate those in Wessex, then the bed complement of units for SSN children in a 'standard' population would increase to the order of about 50 i.e., twice the number proposed by Kushlick.

From our observations, we feel that the application of epidemiological data to the planning of residential and other care for the subnormal has as yet much more limited value than Kushlick appears to suppose. If, by some sort of administrative oversight, a residential unit for a 'standard' population were built which erroneously provided twice the number of beds indicated by the currently available information, it is possible that the unit would be full within a few years. This statement is not an acknowledgement that one of Parkinson's laws operates in the field of subnormality. It is simply a suggestion that there are imponderables affecting epidemiological information which render it somewhat unreliable. At best, it can prevent gross under-estimates of requirements; and for that we can be grateful.

3. CAPACITIES OF SUBNORMALS

Kushlick has shown how the categorization of patients according to their capacities or incapacities determines whether they have minimum or maximum need for residential or nursing care. For example, the SSN children thought to have minimum need of such care were those who were only severely incontinent (SI), or else continent, ambulant and not suffering from severe behaviour disorders (CAN); those having maximum need were the non-ambulant (N-A) and all cases of severe behaviour disorders (SB) with or without severe incontinence (CANT). The classification of adults is more complex (4).

On the basis of questionnaires completed by consultants and ward sisters about the medical and nursing requirements of their patients, McKeown and Leck estimated that approximately half of the cases in Birmingham subnormality hospitals needed the kind of care (investigation, active treatment or the attention of trained nursing staff) which made it essential for them to be in hospital (8). The estimates were questioned by some consultants on the grounds that they were not based on direct questioning to them. In a subsequent investigation in which all subnormal children under the age of 16 and a one-

in-four sample of adults were involved, McKeown and Teruel reassessed the numbers of patients in Birmingham hospitals who did not require continuous and specialist care. In this survey the consultants themselves made the decisions about the type of care required. Approximately one-third of the patients were thought not to need hospital care and about one-fifth were considered suitable for discharge to their own homes or, more commonly, to hostel accommodation. There were additional patients with some special requirements whom it would be reasonable to admit to hostels (9).

The criteria used by Kushlick and by McKeown and Teruel, although superficially different, appear to amount to the same thing; Kushlick based his estimates of the type and extent of care required on the incidence, singly and in combination, of the abilities and disabilities of patients. The categorization of in-patients according to the type of care required in the study by McKeown and Leck was presumably based on an evaluation of similar features. But the investigation by McKeown and Teruel seems to show that perhaps the best estimates are arrived at by combining objective criteria with clinical judgement, the latter taking into account factors or contingencies not apparent in the former.

A recent investigation in the largest subnormality hospital in this province had as its aims the classification of all in-patients according to the criteria proposed by Kushlick, and a concurrent estimate, based on these criteria and on clinical judgement, of the numbers of cases who might be potential candidates for hostel care. Each patient was individually assessed by one of us (B.G.S.) in consultation with the Ward Sisters and Charge Nurses. The findings showed that not only does the general epidemiological picture in Northern Ireland differ from that in Wessex but that the hospital populations also differ in the terms of their abilities. Cases classified as being continent, ambulant and not suffering from severe behaviour disorders (CAN) were as follows: (i) 12 per cent of all SSN in-patient children compared with approximately one-third in the Wessex survey; (ii) one quarter of SSN in-patient adults as compared with two-thirds in Wessex; (iii) over half of MSN in-patient adults compared with four-fifths in Wessex (21). It is clear, therefore, that the numbers of in-patients in this province who are relatively free of physical handicaps and of behavioural abnormalities are fewer than those in Kushlick's survey.

It could be argued that the in-patients who fall into the CAN category outlined above might, in the short term, be suitable candidates for hostel or substitute-home care. But in fact many in our survey

were not. Table II shows that 258 (about one in three) patients were thought to be suitable for hostel care. Only 41 per cent of the less handicapped SSN children (CAN) and only 49 per cent of the same category of SSN adults were thought to be suitable for hostel care. More surprisingly, 14 per cent of

TABLE II

Numbers of in-patients suitable or unsuitable for hospital care in terms of handicaps, age and grade

	Potential hostel candidates		Not potential hostel candidates		Total
	Can*	Can't†	Can*	Can't†	
Children SSN	9	22	13	130	174
MSN	3	—	—	1	4
Adults SSN	61	85	64	287	497
MSN	56	22	20	40	138

* Continent, ambulant, no severe behaviour disorder.

† Non-ambulant, severe behaviour disorder, severely incontinent, either singly or in combination.

the more handicapped SSN children (CANT) and 23 per cent of the same category of adults were also thought to be suitable for such care. A hostel programme started some years ago is expanding, and many of the patients will be moving out of the hospital complex. We cannot, of course, be certain that the patients selected as possible candidates for hostel care will prove, in the event, to be good candidates. Much will depend on the fact that hostel is as hostel does.

May we summarize? The use of epidemiological data in the planning of services for the mentally subnormal is important. But great care must be taken to ensure that there are good grounds for assuming that the prevalence and other rates obtained in one region hold for another. If there is any doubt (and this letter shows that there may very well be doubts), it is worth the expense and time to carry out epidemiological investigations at a local level.

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DEAR SIR,

Drs. MacKay, Scally and Walby kindly sent me a pre-publication copy of their letter in this issue of the *Journal*.

I have since then had a brief opportunity to discuss things with D.N.M. and B.G.S. during a very recent visit to Muckamore Abbey. I will deal with the points they raise separately. However, before doing so I should like to make some general remarks.

I agree that great care should be taken before assuming that 'ascertained' or 'true' prevalence rates found in one area apply to other areas, and that where possible local surveys should be undertaken. However, the most interesting finding has been the extent to which prevalence rates found in different parts of the U.K. have agreed. Moreover, it might have been expected that while overall prevalence rates are similar, in-patient prevalence rates would differ considerably because of the many different policies being applied in different parts of the country.