Prevalence of mental illness among mentally handicapped people: discussion paper[1]

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A recent contributor to the *Journal of the Royal Society of Medicine* reviewed evidence on the prevalence of mental illness among mentally handicapped people, concluding that 'Overall . . . it is clear that psychiatric disturbance is a major problem in mentally retarded patients: estimates vary, but it is probable that around 50% of the population of a mental handicap hospital will pose significant management problems because of psychiatric disorder' (Reid 1983, p 588). Another writer has claimed that on the basis of surveys of hospital admissions and resident populations from the late 1960s and early 1970s, prevalence figures for all forms of psychiatric disorders are 'up to 60%' (Heaton-Ward 1977).

Other evidence gives a very different picture, however. On the basis of surveys in the 1960s in Wessex, Newcastle and Camberwell, three-quarters of mentally handicapped adults living at home, and over half of those in hospital or residential care, do not suffer from either physical handicap or severe behavioural difficulty (DHSS 1971). More recently, it has been asserted that 'It is well-known that not every mentally handicapped person and his family need a psychiatrist. Indeed, only a small proportion suffer from pathological stress, mental illness or behaviour disorder for which psychiatric treatment is relevant' (Bicknell 1983). The Development Team for the Mentally Handicapped (1982) have stated that 'About one in eight mentally handicapped people suffer from major mental illness which will require specialist psychiatric medical and nursing care'.

What is the true picture?

Difficulties of establishing true rates

Any global estimate of the prevalence of mental illness among mentally handicapped people is subject to error for three reasons.

First, no precise count of mentally handicapped people can be made. Until a few years ago, no more than a guesstimate would have been possible; the definition of mental handicap was often determined by criteria such as contact with the relevant services. In individual cases the perception of whether or not someone is mentally handicapped may be influenced by social or environmental factors. The construction of registers has considerably reduced the margin of error, but some mentally handicapped people are always likely to be left out.

Secondly, some surveys are based on hospital populations, some on populations living in other kinds of settings, and others on a combination of both. Hospital populations may contain more disturbed individuals than populations living elsewhere, but there is likely to be considerable overlap, and the extent of the difference is uncertain.

Thirdly, hospital populations have decreased slowly in the last decade, and it is likely that hospitals will contain a progressively higher percentage of disturbed individuals, as less severely handicapped residents take the first places in the queue to return to the community. Yet in recent years figures have been produced with increasing frequency of the substantial numbers – a recent official estimate (DHSS 1981) suggested one third of the total, some 15 000 people – of those currently living in mental handicap hospitals who could live in the community if adequate back-up services were available. Estimates have risen to at least 40% for an individual Region (Roberts & Morris 1983) and over 50% for an individual hospital (White 1983).

[1]Accepted 22 March 1984

0141–0768/84/090761–05/$01.00/0 © 1984 The Royal Society of Medicine

It must be remembered that many mentally handicapped people have always lived in the community, where prevalence rates for mental illness are difficult to establish. Measures of mental illness by general practitioners are notoriously unreliable (Shepherd *et al.* 1981) and some mentally ill people have been found living in the community without any kind of medical assistance (Brown & Harris 1978). Mentally handicapped people in the community do not make great demands on medical care: about three-quarters of one such sample saw their general practitioner no more than twice a year (Ineichen 1980).

In addition, there are special difficulties in assessing the extent of illness among mental handicap hospital residents (*see* Jones 1975, Tibbits 1979). Reiss, Levitan & Szyszko (1982) show how mental handicap can distort diagnostic impressions. Some mentally handicapped people, especially those who have been in hospital for a long time, may be subject to institutional neurosis, in the same manner as has been described for patients in mental illness hospitals (Barton 1976). It has been asserted that simple schizophrenia has few features to distinguish it from the effects of prolonged, unstimulating hospitalization (Reid & Aungle 1974). Assessing, even by sensitive interviewing, the mental health of someone who has lived a life of hospital routine and has become nervous of strangers, presents difficulties. And how many people could have endured the conditions in some of our large mental handicap hospitals over the last twenty years without becoming depressed?

Mentally handicapped people have to face difficulties associated with their position in an industrialized, competitive society. Poor self image may lead them to become defensive and withdrawn and thus prone to a diagnosis of depressive illness (Reiss, Levitan & McNally 1982). The inverse relationship of social class and mental illness is too well known to need elaboration here.

Other difficulties concern the relationships of mentally handicapped people. Many have to cope with the stressful circumstances of parental rejection (Reiss, Levitan & McNally 1982). Others, in contrast, may be over-protected by parents and thus ill-prepared for their eventual loss (Ineichen 1980, Wertheimer 1982). And as they grow through childhood, they also face rejection by their peer group (Reiss, Levitan & McNally 1982, Reid 1982). The structure of their opportunities in daily living, which inhibits their meeting with non-handicapped people except as service providers (in segregated day centres, for example), adds to their isolation. The emotional life of many mentally handicapped people is notoriously impoverished.

The evidence reconsidered

Many surveys of diagnosed mental illness among patients in mental handicap hospitals give a prevalence figure of between 10 and 14% (DHSS 1972, Forrest & Ogunremi 1974, Tibbits 1979, Wright 1982, NE Essex Health Authority 1983). The DHSS study is particularly important because of its size: the authors consider the figure 'almost certainly an understatement' although it includes mentally handicapped people in mental illness units. Craft (1959) gives a lower figure (7%). Higher figures of 27% and 31% are given by Challis & Shepherd (1983) and Ballinger & Reid (1977); Corbett (1979) includes 'behaviour disorders' and people with past histories only of psychiatric conditions in his figure of 46%. Williams (1971) gives the highest figure of all (58.8%) although only 15.8% are rated severe. Such patients 'require continuous and perhaps intensive in-patient care from psychiatrists' while the rest require 'at the most occasional psychiatric specialist attention'. But this study also identified 38.8% of those living in one hospital as capable of managing in a sheltered environment, or with 'checking and counselling only'. Even 20% of those reckoned to suffer from psychiatric disorder were defined capable of surviving with community care.

Not surprisingly, ratings of vaguer measures of social maladjustment produce higher rates. Including measures such as behaviour problems and psychiatric symptoms (however defined) gives a range which stretches from 23% (Wright 1982) through 27% (DHSS 1979), 32% (DHSS 1972), 40% (Craft 1959) and 52% (Ballinger & Reid 1977).

Leck and his colleagues (1967) give a figure of 37% for those receiving treatment for neuropsychiatric conditions. Yet several writers also point out that a substantial proportion

of their sample require no nursing or medical care. As mentioned earlier, Williams (1971) gives a figure of 38.8%; Leck and his colleagues (Leck *et al.* 1967, McKeown & Leck 1967) suggest over half, based on an appraisal of medical, nursing and other needs, although consultants alone give a figure of 30% for adults and 14% for children (McKeown & Teruel 1970).

Other studies are more disparate and very difficult to compare. Reid & Aungle (1974) report a prevalence rate of 7.1% for senile dementia among 155 hospital patients over the age of 45. Ballinger & Reid (1977) give figures of 13% significant psychiatric disorder and 41% symptoms among an adult training centre sample. Udall & Corbett (1979) found that 16% of the residents of local authority hostels were reckoned by wardens to pose severe management problems. Richardson *et al.* (1979) give a figure of 46% for behaviour impairment over the lifetime of a sample of 190 Aberdonians aged 22. Corbett (1979) gives a figure of 37.2% of his sample (people living at home in Camberwell, known to be in contact with services) for whom a psychiatric diagnosis could be made; as with his hospitalized sample mentioned earlier, this includes both people with a past history only and those with 'behaviour/personality disorders'. Among a sample of 140 Camberwell children, of whom one-quarter where in residential care, 47% showed significant behaviour disturbance. Primrose (1971) found that 8% of his sample were admitted for reasons of psychiatric disturbance; another 50% were for antisocial behaviour, a majority of which were for 'acts which would have been considered criminal had they been done by an adult of normal intelligence, though usually part of a pattern of behaviour rather than an isolated incident'. Studies of psychiatric state at the time of hospital admission may of course reflect local admission policies, as well as the adequacy and competence of community services.

No study is known to the present author where the rate of mental illness among mentally handicapped people reaches 60%.

How different are mentally handicapped people?

Mental illness is common among non-handicapped people. A frequently repeated statistic suggests that one woman in 8 and one man in 12 may be hospitalized for it at some time in their lives, although modern trends towards crisis intervention without hospitalization, and improving community care, should reduce that figure.

Mental illness in general populations is very common. One study of Crawley, Sussex (both the old and the new towns) found that over 40% of women of child-bearing years had consulted their general practitioner for a neurotic problem, leading the researcher to conclude that neurosis was almost normal among women of that age group (Clout 1962). Yet no one suggests that they should receive specialist psychiatric provision, nor that most of them should be in psychiatric care.

The high rate for treatment for neuropsychiatric conditions reported above by Leck *et al.* (1967) may result from the kind of therapeutic regimen that prevails in hospitals: 68% of a sample of mentally handicapped people in Harperbury Hospital were receiving drug treatments, a majority of which were tranquillizers (Hughes 1977). In some instances such treatment may be introduced as a form of social control (Ryan & Thomas 1980, p 53). An investigation of hostel residents found a higher usage of medication in NHS than local authority hostels, perhaps due to the greater likelihood of prescribing drugs in a health service setting (Malin & Race 1979).

Psychiatrist's role with mentally handicapped people

How can psychiatric services best be provided for mentally handicapped people? The reasons why large numbers of mentally handicapped people are currently in NHS care are historical ones and have little to do with the specific nature of their needs. As one writer puts it, 'There seems no valid reason for using doctors who have had a lengthy psychiatric training to obtain and administer the social and educational needs of the large number of institutionalised mentally handicapped people in this country' (Williams 1971, p 39). Another states: 'The question for psychiatrists is not whether the mentally handicapped

should be in hospital, but which patients require hospital places on psychiatric grounds and what can be done to ameliorate their condition once they are in hospital. Like their more intelligent counterparts, some mentally handicapped patients may need psychiatric admissions on a short-term basis only' (James 1980).

It must also be remembered that most mentally handicapped people have always lived outside hospital. The substantial number of those presently in mental handicap hospitals who could live competently in the community, if adequate alternatives were available, has already been indicated. Mentally handicapped people may be capable of learning to a far greater extent than has been thought possible: their limitations, it has been argued, may be as much in our inability to teach as in their inability to learn (Mittler 1979).

Mentally handicapped people in hospital have themselves shown a strongly expressed wish to leave hospital to go home (Ballinger 1973). How successful they are in achieving this end should depend not only on factors of personality and temperament (Reid 1983), nor even on their capacities to learn and adapt, which can be greatly influenced by the amount of help a mentally handicapped person receives (Ryan & Thomas 1980), but on the provision that is made available to them, the choice that is offered. With greater general acceptability of the idea of mentally handicapped people leading lives integrated into society, what is now needed above all is the political will to ensure that the provision of such choice becomes a practical reality.

Such choices may prove to be no dearer than hospital services, though there is no guarantee that they will be cheaper. They do not, as has been claimed (Reid 1983), 'come down in final resort to matters of finance'. There is no golden rule about the relative costs of hospital-based or community-based services.

The best way to reduce mental illness and behaviour problems among mentally handicapped people is to remove the conditions that do so much to bring them about. This means providing above all the opportunities for ordinary living that non-handicapped people take for granted.

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