The need for asylum in society for the mentally ill or infirm

THE THIRD
KING'S FUND FORUM

Consensus statement

King's Fund

The third King's Fund Forum was held in London from 8 to 10 April 1987. A panel of twelve from a range of backgrounds listened to evidence from experts in public sessions attended by 200 people, including representatives from many consumer and voluntary organisations as well as health care and social service professionals. After closed sessions the panel discussed its report with the audience; the agreed consensus statement was then presented at a press conference.

The conference was asked to confine its attention to three groups of people who might need asylum:

1 adults with persistent major mental illness including the mental illnesses of old age and dementias;

2 the mentally impaired with behavioural problems;

3 people who are aggressive or have seriously irresponsible behaviour.

The definition of 'asylum' given to the conference was: 'A safe place of refuge or shelter, providing protection and support which may or may not involve total or partial withdrawal or removal from the rest of society. It may or may not involve treatment'.

The conference has been concerned with 'asylum', a word which evokes a cluster of images. Some are positive ('shelter', 'retreat', 'sanctuary') others are darker, resonating in the public consciousness with the madhouse of the Victorian era. We have used the conference definition to seek a modern interpretation of the function of 'asylum' in this first, positive sense.

The evidence of history indicates the existence of an enduring body of disordered people with a need for care who have proved resistant to treatments of the day and are not tolerated in their society. Those offered 'asylum' have been chronically mentally ill, elderly and mentally handicapped people, who were homeless and friendless and who could not be contained within their families. Relief was given to families by removing the responsibility for caring when family tolerance was declining.

Various social changes, the advent of pharmacological treatment and social security benefits, have reduced the necessity for 'in-relief'. This has decreased the numbers in large long-stay hospitals. Critics have justifiably challenged the status of the large mental hospitals which contribute to the disability of patients. Despite reforms, those mental hospitals have become

symbols of the outdated. Present concern with 'asylum', as an alternative to abandonment, does mean acceptance of the essential chronicity and intractability of many psychiatric disorders.

We are conscious that the winding down or closure of the large mental hospitals is proceeding at differing paces in different localities. Where this may lead to a loss of 'asylum' and its consequences (misplacement or homelessness) either through lack of appropriate planning or failure of proper investment in community services, we believe this is wrong. The development of replacement local services concurrently with hospital closures is critical in maintaining the confidence of recipients, carers and professionals in the new local service, and as a guarantee against loss of service during the transition.

The panel addressed together two of the questions asked (Questions 1 and 3).

Question 1

Who might need some sort of 'asylum', for what reasons and for how long?

Question 3

What alternative types and levels of 'asylum' should be provided for those needing it, having regard to acceptability and benefit and to feasibility in terms of organisation and cost?

The British model of care is strongly rooted in the concept of providing services to meet the needs of a geographically defined population. Existing data do not provide a sound basis for drawing conclusions about the frequency and nature of psychiatric disorders, and this is a fundamental barrier to diagnosing the community's needs.

We believe that the psychiatric case-register concept and population based surveys of the prevalence of dementia, which were described to us, provide examples of the kinds of epidemiological data which are close to what is required. Greater account should also be taken of socio-demographic differences between populations when planning services.

We accept, too, the importance of broadening the basis of the definition of need in individual patient groups to provide a common currency for the

multiple agencies involved in providing care; to place a greater emphasis on functional capacity; and to ensure that the user perspective is fully incorporated.

In addressing ourselves to Question 1 we have related it to the three main groups of adults identified in our remit. We have used medical diagnosis as categories; clearly behaviour and personal need, not diagnoses, are paramount.

1a) **People with functional psychoses and some severely neurotic persons**

Schizophrenia. There is a need for people with schizophrenia and their families to feel that the sufferer is able to have acceptable accommodation and support. This relieves tensions in the family, and gives respite to them as well as the sufferer. Individuals unable to look after themselves adequately in relation, for example, to diet, clothing, heating and to avoid recurrent infringements of the law (usually obscenity, and petty crimes) will need help. Other dangers include serious crime and the infliction of self injury. It is important not to exaggerate these in a way which too readily limits the individual's freedom. 'Asylum' should be offered on an informal basis whenever possible. The views of the patient (or any advocate) and the family, if they are the carers, should be diligently sought and carefully considered.

Affective psychoses. Some numbers of persons with affective psychoses (primary disorders of mood) require, usually on an episodic basis, 'asylum'. Self harm when depressed, as well as sexual, financial and other indiscretions whilst manic are the main problems. However in manic states, rejection by the family is quite frequent.

Neurotic illnesses. Severe neurotic illnesses, rarely but occasionally produce such obsessional, hysterical and anxious states that asylum is required. Such people require some on-going support to improve their ability to cope, despite their difficulties. Ideally a persistent and forceful therapeutic attempt to improve their predicament more fundamentally is needed.

1b) **Demented people (and others with clearly organic brain disorders)**

We have separated this group from 1a) because there is no real scope for pharmacological treatment of the illness per se, and no discussion about

the role of interpersonal relations in the aetiology. Still it is important to encourage imaginative and humane approaches to the management of their conditions, and certainly to offer support to the family. This is a large and increasing group.

The families of demented people should not be left overwhelmed. They need to be reassured about risks that must be taken, if liberty is not to be too severely restricted (for example, getting lost in the street, leaving the gas on). With reassurance and respite, the need for 'asylum' can be delayed, carefully planned and if possible introduced gradually. In the end, it is frequently necessary either because there are no relatives or they are too old, or because of the complete incapacity of the old persons to live normally. Old people like this can be exploited ; they can sometimes be aggressive; men can present sexual behaviour with which it is difficult to cope. The commonly concurrent physical illnesses of old age also lead to need for supervision.

2) **Mentally Impaired People**

A small number of mentally handicapped people require 'asylum' for their intellectual impairment itself; however mental handicap can be associated with behaviour disorders. The latter involve stealing and aggressive, destructive, and self-mutilating behaviour and which can lead to their rejection. Technically this category does not include autistic adults, but they may have similar needs for 'asylum'. It is for those whose behaviour disorder has not responded to treatment, and particularly when the carers are aging, that some form of 'asylum' is indicated.

3) **People who are persistently aggressive and who have other irresponsible behaviour (in a mental health context).**

We include here substance abusers, because they are involved recurrently in illegal behaviour, and might be said to display personality disorders. They often need rehabilitation hostels offering, for example, therapeutic community regimes for periods of up to a year.

Persistently psychopathic people present one of the most difficult groups for whom to provide, as there is no agreement about who should be responsible. They recurrently appear as psychiatric outpatients, as well as in court. The need for 'asylum' for this group is primarily because of their difficulties in taking responsibility for their actions; this is possibly best provided in therapeutic communities or hostels.

For all these people, however, it is not easy to use the word 'asylum' to produce answers. The concept involved is a range of opportunities for safekeeping.

It is certainly possible to provide 'asylum' as defined. However it is considered that the concept is likely always to involve 'treatment' or care, but only if that is taken to include nursing, habilitation and rehabilitation in the widest definition.

In an even broader sense, some form of refuge may be wanted by people outside these categories. What matters is to start with the people, see what they need and then design facilities to meet their needs. As the needs will be diverse, so should the facilities. Quality will be assessed by relevance to each of those needs.

In the past the tendency was to provide the buildings and then try to fit the recipients of care and their needs into them. This should not happen, especially as needs can change more quickly than buildings can be put up.

The range of needs will vary from meeting a short crisis to long term residence. The latter can be the more difficult. The cause may be senile dementia, which will not improve; it may be behaviour which is just not acceptable to society, and in some cases this can be improved. There are illnesses which mean a long stay in a suitable caring institution. For those people, the place where they are will be their home for a long time. Large wards in large institutions cannot and should not be regarded as 'home' for anyone.

A number of other important facilities are also required. The needs they meet are, for example, those of people who are making their way back from severe mental disorder into some sort of independence. There are also fluctuating illnesses which need treatment in different environments at different times.

Whilst we received no detailed evidence, we recognised the importance of planning for the needs of at least two other groups. First, the predicted increase in numbers of people with the Acquired Immune Deficiency Syndrome (AIDS) and the advent of new generations of drugs to prolong survival, will mean a sharp increase in numbers of people in this category with mental disorder. Second, it is important to resolve the more long-

standing problem of devising an appropriate model of care for younger people with severe long-term effects of brain damage.

There is the difficulty of care being provided by a variety of agencies. Examples are: inappropriate placement of people in different types of care; apparent duplication of provision to some recipients; the existence of others, in need, who are not satisfactorily helped. At worst, services could be described as 'fragmented', at best as a 'spectrum' of provision. However they are far from being a continuum operating as an integrated whole, matching help to need in an appropriate way. Any use of private services by the statutory agencies must be specifically planned as part of a local network of services and properly regulated.

This has so far not been resolved by joint planning between health, social services and other authorities. Services must be able to provide individual care plans for each person, together with the possibility of moving between different kinds of care, and also moving out altogether. The minimum aims must be to reduce behavioural disturbance and to improve each person's ability to cope, or at least retain such competence as exists; and that is crucial for long-stay patients as well.

Versatility will lead to greater response to innovative ideas; authorities and staff should look out for these, and see if they are suitable for implementation. Such practices, however, need much greater flexibility in funding, as between health (regions and districts) and social service authorities. Evidence suggesting a new statutory agency is not supported but an overhaul of current arrangments would often lead to a better use of scarce resources. Consideration should be given to one of the agencies taking prime responsibility for running the services. Better financial incentives are needed to improve joint planning leading to more coherent services. Another way to improve planning is to involve the local community and, if possible, users.

There are examples of good practice in hospital and community provision in various parts of the country which work well in their local setting. The charismatic leadership which has led to some of the successes may not be easy to reproduce, but more should be done to publicise good practice. The system outlined above will not appear everywhere overnight. This transition must acknowledge the fact that, for example, a large number of dementia patients are still in traditional psychiatric hospitals.

The DHSS's stated policy is to provide a comprehensive mental health service on a local basis. So expressed we would agree. As the range of services increases and improves, the number of hospital beds will be reduced; although there will remain an irreducible minimum. That presents a challenge alike to authorities and agencies in the health district and to their staffs. For the authorities (and central government) it may involve a reversal of priorities. Patients in the groups defined above should not be at the tail of the queue for care. Their needs should be at the top. The greater their dependency, the greater the case for positive discrimination. The public will have to be educated in this change. A commitment to a first class mental health service should be judged as urgent as, for example, a first class service for rapid hip surgery. Improvement of the image of mental health care may be hard work, but it must be done.

That should bring a double benefit. The whole range of staff, too, the most valuable resource of all should be able to enjoy a greatly increased status and esteem. It does not follow that, in future, qualified nursing staff will be required to fill all the roles. To complement their contribution, thought should be given to training people with other skills to participate in the new and more versatile system.

Such a service is much more likely to be attractive to the recipients of care and their families and these recipients would be more likely to stay in their own homes. There would be scope for choice, or even negotiation. The service should be accessible over 24 hours, seven days a week. The community would come to appreciate that, for every mentally disordered person's needs, a suitable facility exists; that should reduce apprehensions. Sometimes, a person will still have to be detained by compulsion but the development of a range of facilities will provide a greater opportunity to choose the least restrictive alternative. When detention is necessary it should be subject, as now, to statutory supervision.

Question 2

What happens if there is insufficient provision of appropriate 'asylum' for people considered to need it?

This situation inevitably leads to social breakdown, increasing disability and, probably, isolation. It may result in the criminalisation of certain aspects of disturbed behaviour, leading possibly to imprisonment. The evidence is that mentally disordered people are in prison who should not be there.

Abnormal behaviour may also lead to a loss of accommodation, and if permanent homelessness is the consequence then the person may be left vulnerable to abuse and even a danger to both themselves and to others. There are also misplaced referrals and inappropriate admissions. The end result may be totally unsatisfactory. Therefore the provision of an appropriate form of 'asylum' will be cost-effective, and may also prevent deterioration of the individual and the family, and the misuse of other expensive facilities.

We are fully committed to the policy of care in the community. There is however clear evidence that a product of the change is often a quite unreasonable burden being placed upon carers. This burden can lead to great distress and even emotional breakdown. In the planning of resource allocation, the interests of the carers have not been taken properly into account.

Evidence before the conference suggests that some mentally disordered people, and/or their families, battle on without any form of assistance. There are at least three possible reasons for this: a perception that the institutional care is not acceptable; negative attitudes on the part of the referring professional; and the inability, or unwillingness, of the services to cope with the problem. Carers may not be the first to ask for help; yet it is not automatic for the community mental health services to keep track and look out for signs of crisis. These services should discuss with the carers plans for the patient. This is not just a matter of what the patient might choose, but of what is also necessary to meet the needs of carers.

There was also evidence of the importance of funding a range of facilities able to respond to a variety of special needs encompassing age, physical and psychiatric conditions. These should provide both short and long-term care, and control and treatment based upon an assessment of each individual; but where appropriate this must be in the context of the family as a whole. This is elaborated on under the earlier questions.

Question 4

How should the quality of 'asylum' and the adequacy of provision be monitored and regulated?

The modern concept of 'asylum' programmes, whether in a hospital or anywhere else, should demonstrate characteristics which attach explicit

social value to the recipients of care and the staff providing it. This implies recipient rather than staff orientated regimes of care which emphasise choice and autonomy characterised by:

- no regimented care or treatments;
- personal space and privacy (own room, own possessions);
- participation and relationships with non-disabled people;
- minimum restriction on movement;
- facilities which minimize segregation but which recognize the individual needs of staff and recipients for privacy;
- an attractive small scale physical environment (which would be regarded as generally appealing);
- individuality in dress and appearance;
- taking responsibility for every day tasks (washing, cooking, laundry);
- help in achieving greater competence, if possible to obtain work or occupation;
- respect for recipients by others;
- proper receipt of financial benefits.

Whilst a variety of mechanisms already exist to monitor the quality of services for mentally ill people, the concept of evaluation should be broadened and extended. This includes both external monitoring and internal regulation, achieved by high levels of staff training and sensitivity to individual needs of recipients.

Individual needs and the development of remedial programmes will be a matter for determination and review through regular discussion with recipients, their families and other staff. We consider that advocacy schemes, including self-advocacy, may be a way to ensure that the voice of the recipient is heard and acted upon.

Finally, the scope of the conference was deliberately limited and did not deal with primary care, children, disturbed adolescents and political 'asylum'. However we believe that six issues are of such importance that investigation and further research into them should be urgently reviewed. They are:

- ways of preventing mental disorder;
- assessment of the real needs of mentally disordered people, including local or regional variations – such assessment is vital for proper planning;
- cost-effectiveness and cost-benefit of different forms of care – such information would greatly assist allocation of funds;

- manpower and training implications of running a new style mental health service;
- the possible role of ethical committees;
- ways of providing a safety net for those who nobody will accept.

The panel comprised: Lord Colville (Chairman), Mr Paul Beard, Dr Douglas Bennett, Baroness Blackstone, Mr David Bowden, Dr Kenneth Boyd, Dr Liam Donaldson, Professor Alec Jenner, Ms Tessa Jowell, Miss Joy Kinsley, Mr Herbert Laming, Ms Usha Prashar.

Invited experts presenting evidence were: Professor T Arie, Dr D Cunningham, Dr D Dick, Mr S Etherington, Professor D Goldberg, Professor J Gunn, Mr C Heginbotham, Professor W Parry Jones, Dr E Johnstone, Dr K Knapp, Ms S McKechnie, Ms A Norman, Dr J Reed, Dr F Seymour, Dr G Shepard, Mrs D Silbertson, Dr D Towell, Mrs S Turner.

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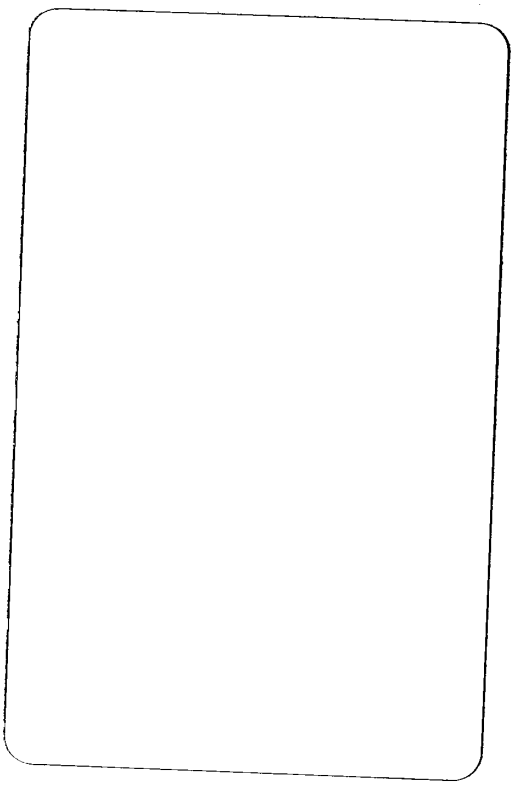

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