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PRIME MINISTER 10 March 1989

COMMUNITY CARE - SOME FUNDAMENTAL ISSUES

The Griffith's Report will be discussed on 21 March. I will put in a detailed note on the subject next weekend. In the meantime, you may be interested to see a note by Marjorie Wallace of the charity SANE (Schizophrenia - A National Emergency). The note tackles some of the fundamental issues of community care and her concerns over the politicisation of the debate.

Polarisation of the debate - the mentally ill

There is a clear need for a wide spectrum of care ranging from secure accommodation for the severely mentally ill at one extreme to support in the family home at the other. But some organisations notably MIND - are polarising the debate. In a recent article in the Independent, MIND accused SANE of supporting the call for a return to the old days of large impersonal asylums. This claim is simply untrue. This view appears to derive from an ideological concern over the 'freedom of the individual' rather than a desire to cure an illness and to give support to families in the community.

For many years MIND has been the major political voice in the mental health field and the first point of contact for the media. But the views of MIND's central organisation now appear to be in conflict with many of its members on the ground. A few local groups - in Gloucester for example - have disassociated themselves from MIND for this reason. Even so, MIND remains as a highly influential lobbyist.

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Five members of MIND's council of management are former patients in a mental hospital. And the Vice-Chairman believes he was wrongfully detained and drugged in an asylum. Also, some factions within the organisation such as 'Mind in Camden' believe that schizophrenia is not an illness but a 'human life problem', a constraint imposed by society.

Scientific evidence is clearly to the contrary. First there are structural changes to the brain such as a mild degree of enlargement of the ventricles. Second, there is a positive reaction to drug treatment by acute sufferers. Third, stress does not cause schizophrenia. It can only aggravate it.

Conclusion

There is a danger that the debate over the Griffith's Report will fail to address some of the fundamental issues.

One unified mechanism will not solve the problems of all the priority groups together (mentally ill, mentally disabled physically disabled and the elderly). The severely mentally ill will need intensive health care. Some elderly may just need practical support in the home.

And family carers should have more say. The ideological views of organisations such as MIND have caused distress to families. For example, some families have been made to feel that the 'home environment' has caused the problem.

As the community care debate develops in the coming weeks, these fundamental points will need to be considered.

Ian Whitehead

IAN WHITEHEAD

5 March 1989

WHY SCHIZOPHRENIA HAS BECOME A NATIONAL EMERGENCY.

Notes by Marjorie Wallace

THE SCALE OF THE PROBLEM.

1. Schizophrenia, "The Forgotten Illness", is the most common form of serious mental illness. It affects 1 in a 100 people at some time during their life. Current medical evidence strongly favours the view that it is caused by some biochemical imbalance and that victims have a genetic vulnerability which can be triggered by some conditions including conflict and stress. There is no known cure. About one third eventually recover from their first attack, a third suffer recurring bouts of illness throughout their life, and a third never recover. Since it is an affliction where the inner torment of sufferers is often focused on the people closest to them, at least a million people in the UK are involved.

THE SYMPTOMS.

3. The onset of schizophrenia is normally among teenagers and young people before the age of 25, although in women it may appear later, sometimes after childbirth or during the menopause. Because it attacks young healthy people at the start of their productive careers, its economic cost is enormous. Schizophrenics can rarely sustain work and are a burden on the taxpayer throughout their lives. The symptoms of the illness are variable. The sufferer may hear voices which threaten and bombard him. He may believe that his innermost thoughts are being overheard; he may hear "messages" directed to him from TV and the radio or the tannoy system. He may live in terror, believing that his family have become spies, that his colleagues are trying to poison him or that the secret services are pursuing him. The symptoms may be less dramatic, sometimes indistinguishable from normal teenage problems. A previously normal and happy young person may gradually lose friends, fail exams or jobs, become lonely and withdrawn, pace the room all night and sleep by day and neglect his or her appearance. He may become emotionally "flat" or aggressive especially towards those closest to him.

WHERE SCHIZOPHRENICS LIVE.

3. At any one time there are about 250,000 people in Britain suffering schizophrenia attack. Most of them (90%) are living in the community. For many "community" means their families - often ageing parents or widowed mothers exhausted from maybe 20 or more years of living under the tyranny of a profoundly disturbed son or daughter. A lucky few live in hostels and sheltered accommodation from which they are evicted if their illness makes them behave badly, many more are put up in bed-and-breakfasts, private sector hotels and often squalid lodgings from which it is all to easy to drift into destitution. 20,000 of the worst cases

are occupying hospital beds - more than any other disease, including cancer and heart disease.

SUICIDE RISK

4. Since people suffering from schizophrenia are not physically ill, the direct mortality is low. But such is the mental torment that many sufferers are led to commit suicide. Reliable statistics are not available, but it has been estimated that 1 in 10 eventually commits suicide. The risk is much greater if they have been allowed to fall out of the network of care and forget the medication which can stabilise them.

THE URGENCY OF THE SITUATION.

5. During the past six years I have travelled around Britain and interviewed hundreds of families and sufferers. I have talked to doctors, psychiatrists, health authority and local authority managers, police, magistrates, social workers, community psychiatric workers and other professionals. I have travelled to rural areas, market towns, suburbs, inner cities. Wherever I have gone I witnessed the same devastation wrought by the illness and heard the same heart-breaking stories of lack of understanding and help for sufferers and their families. In the course of this and in response to articles, I have received well over a 1000 desperate cases. A few of them have been portrayed in my articles and in my film "Whose Mind Is it?" They are not one or two tragic cases which have slipped through the system. In my experience, they represent the norm.

6. One mother I know, whose son, a gifted academic broke down in his twenties and has been ill for 10 years sums up the sadness. "It is like a continual bereavement. The loss of your son´s potential, the pain he goes through and the way people lose interest when he doesn´t get better."

7. The inability of the current health and social services to deal with schizophrenia has alarmed me more than any other social or medical problems I have encountered in in over 15 years in investigative journalism. That is the reason I have, with the backing of my organisation, spent these years campaigning for greater awareness.

THE LACK OF EDUCATION

8. In spite of the scale of the problem, its high economic cost to the nation, and the severity of its effects, schizophrenia has been largely ignored. A recent survey carried out for SANE showed that it was the least understood and (next to Aids) the most feared illness. Millions are being spent on educating the public about Aids, but nothing about schizophrenia. Even doctors, social workers, magistrates and police who confront the problem do not recognise the symptoms or understand the nature of schizophrenia.

THE LACK OF MEDICAL RESEARCH

8. Only 0.5 per cent of the Medical Research Council's budget is spent on research into the disease. Even as a charity, it comes bottom of the league along with most other mental illness. Only 1 per cent of all charitable donations go to mental illness, and schizophrenia receives only a small proportion of that.

WHY COMMUNITY CARE HASN'T WORKED

9. A great deal has been written about community care and the way in which successive governments have implemented the de-institutionalisation policy since Enoch Powell's famous "water-tower" speech in 1961. (In fact the reforms came even earlier in a Royal Commission Report on the law and mental illness and the Mental Health Act 1959.) I do not propose to repeat the literature which was formalised in the White Paper "Better Services For the Mentally Ill" (October 1975).

10. With the discovery in the 1950s of anti-psychotic drugs such as Largactil which could control the more florid symptoms of schizophrenia, it became possible for many patients to live outside hospitals. For some this was a welcome and necessary freedom, an end to overcrowding and inhumane custodial regimes. Britain pioneered the "open door" system whereby most patients became voluntary and went in and out of hospital according to their needs.

11. Then in the 1960s in the USA there was a strident anti-psychiatry movement which condemned all aslyum care. This was fuelled by ideas about mental illness which replaced the old "medical model". Thomas Szasz put forward his belief that there was no such thing as mental illness but that it was a social construct used as a means of political control. R.D. Laing in this country placed the emphasis on irrational parents and a society to which the sufferer was reacting rationally.

12. The concept of "normalisation" became fashionable - that is, if you treat a person as normal, they will become normal.These ideas became involved with the civil liberties movement in the USA and caught up in a mishmash of other 60s movements in the USA and Europe, from Flower Power to neo-Marxism.

13. Although they seemed enlightened at the time, most of these theories have since been discredited. It is ironic that just when the evidence points to a medical basis for the illness we have been left with a policy which relies on muddled ideologies which do not accept this basic premise.

THE RESULTS OF DE-INSTITUTIONALISTION.

14. In the USA and Italy, the rapid emptying of asylums proved disastrous. It is estimated that over 50 per cent of the homeless on the streets of New York are discharged patients. Others sleep in huge shelters, where they are minded by security guards in

place of nurses.

15. In Britain we are going the same way. St Mungos the charity for single homeless men estimate that numbers of ex patients in their hostels has increased four-fold in the last five years. The Salvation Army has had to close its doors on seriously disturbed people. Prison doctors tell me that they are concerned by the increasing numbers of mentally ill who commit petty crimes to find refuge.

CONFUSING MENTAL ILLNESS WITH MENTAL HANDICAP AND OTHER DISABILITIES

16. The community care policy has in my view wrongly equated the needs of mentally ill people with those of mentally handicapped, physically disabled, and elderly people. Discharging mentally handicapped people from big hospitals into small hostels in the community and training them to look after themselves can work well, although the cost especially in terms of the ratio of staff to patients, can be very high.

17. People with serious and cyclical mental illness present different problems. A schizophrenic Oxford graduate knows perfectly well how to pay a bus fare, or boil an egg. But the supervision of an untrained landlady or the occasional visit from a homehelp or even social worker may not be sufficient to recognise when his inner turmoil will drive him to desperate behaviour.

THE CATCH 22: COMPULSORY TREATMENT

18. Schizophrenia is a rogue illness. The more severely ill the sufferer is, the less able he is to know he needs help, and the less likely to have the insight, drive and motivation to seek it. Drugs can often stabilise the condition of a schizophrenia sufferer, just as insulin will stabilise a diabetic. If the diabetes goes out of control, the patient goes into coma and no doctor would hesitate to treat him without his consent. But the schizophrenia sufferer, when his disease is out of control remains conscious, deluded, but often plausible.

19. This poses a dilemma. Current emphasis on "patient power" such as is held by factions within MIND, the training of social workers, together with a an understandable reluctance to deprive someone of their liberty has led in my experience to the most poignant tragedies.

20. The typical story I get goes like this. A young man (or woman) is discharged from hospital or leaves of his own accord. While stabilised on medication he may be able to think reasonably clearly and contain his inner distress. But the drugs cause unpleasant side-effects and without encouragement he may cease to take them, stop going to out-patient appointments, sleep all day and not turn up at the day centre. When the community psychiatric nurse calls, he may not answer and a card is left on the door mat. He begins to deteriorate. His voices and delusions overwhelm

him, he neglects his appearance and deteriorates. His relatives watch this happen but can do nothing. No-one can interfere until often it is too late ; he goes missing, he assaults his mother, jumps from a window or his body is found on a railway line or as in a recent case a girl walked down the centre of a motorway, dressed in black, and was killed. The girl was already under a section for holding a family at gun point. As in many of these cases, the outcome was predictable but no-one had the power or will to intervene.

THE MENTAL HEALTH ACT 1983.

21. While some of the reforms in the 1983 Act are excellent, they are open to misinterpretation. According to Professor Bluglass who chaired the commission which drafted the legislation it has made it "more difficult to admit patients compulsorily to hospital, easier for patients to obtain a discharge and harder to control patients with continuing illness in the community."

22. It is not so much these changes but the climate which puts patients rights paramount, the opposition of social workers who have been trained in the civil liberty background and the fear of some doctors to implement the spirit of the act which has led to patients being denied help they may need. For this, more leadership is needed both from the psychiatrists and government.

THE CHARITIES INVOLVED

23. Apart from the Mental Health Foundation, which gives grants to projects in mental handicap, mental illness, there are only three charities specifically involved with schizophrenia. The National Schizophrenia Fellowship which started as a network of self-help groups for sufferers and relatives has recently become more vocal against the policy of closing mental hospitals. The Schizophrenia Association of Great Britain is a small charity devoted mainly to supporting medical research into the illness, with emphasis on diet.

24. SANE (Schizophrenia - A National Emergency) is a charity formed as a result of the response to my articles in The Times. It is a catalyst campaigning organisation which seeks to raise funds for: (1) medical research into the cause, eventual cure and better treatment of the illness; (2) promoting better support for sufferers and families through (a) research into community care (b) funding of other charities providing services and (c) some innovative care projects; (3) to raise awareness in the community, among professionals and policy makers.

25. SANE believes that only by breaking the apathy and stigma which surrounds schizophrenia and making the public understand that it is an illness which is not the fault of the families or the sufferers can any progress be made.

HOW MIND HAS POLARISED THE DEBATE .

26. It is on this fundamental point that SANE (and the SAGB and the NSF) differ from the charity MIND, an organisation now devoted to fighting for the rights of mental patients. It has had links with the civil liberties movements here and in the US, and at one stage was infiltrated by the scientologists. During the 1970s under the leadership of ex civil liberties' director, Tony Smythe, it took on a more legalistic and lobbying role and through importing the American lawyer Larry Gostin, was instrumental in introducing changes into the Mental Health Act 1983.

27. MIND also adopted many aspects of the anti-psychiatry movement and supported the programme of closing asylums and discharging patients into the community. It blames the current crisis on the government for failing to provide sufficient funds for alternative facilities in the community.

28. In the past few years MIND has become split by a radical faction within its central organisation whose views are not held by most of its members on the ground. It has also been taken over by some extreme groups such as CAPO (the Campaign against Psychiatric Oppression), Survivors Speak Out (who speak of hospitals as internment camps and psychiatrists as oppressors) and groups such as "Mind in Camden" who put forward the view that schizophrenia is not an illness, but a " human life problem", a construct imposed by society.

29. These "patient power" or "user" groups are currently fighting for power within MIND and have become violently opposed to any organisation which believes in the medical basis for mental illness. They are therefore anti-hospitals, anti-medication and anti any labelling of illness or "treatment".

30. In the course of this battle, MIND has recently changed its chairman, it has no current president or director, and appears to feel threatened both internally and externally. Its vice chairman, Mike Lawson, was a patient who believes he was wrongfully detained and drugged in an asylum. Many of the new more militant members are also patients who feel they were unsympathetically treated by the medical profession. Or they are lobbyists for other minority movements who have attached themselves to this cause. Professor Anthony Clare is among a number of eminent psychiatrists have disagreed with and left the organisation.

31. For the past 25 years MIND has been the major political voice in the mental health field and the first point of contact for the media. It resents the new high profile for families' rights expressed through SANE and the NSF. It accuses them of forming an authoritarian backlash: "A return to asylums, drug treatment and containment."

32. At no time has SANE campaigned along these lines. SANE has called for postponement of the hospital closure programme until (a) surveys and research have been carried out to show that the policy works, for whom it works, and what kind of care can realistically be substituted; (b) it can be proved that patients are not discharged back to families who cannot cope or into hostels, bed-and-breakfasts and other private sector lodgings from which they can drift into destitution (23,000 hospital beds have been closed in the last 10 years and only 4000 residential paces provided in the community.); (c) sufficient hospital care is available to provide proper refuge when crises occur or long-term care is needed.

FIRST STEPS TOWARDS A SOLUTION

33. There is an obvious need for more day centres, hostels and other facilities. But there is no point in pumping more money into local authorities for community care until the fundamental issues have been resolved. This involves research (see paragraph above) and proper quantification of the problem. Piecemeal provision of extra facilities by local authorities will not solve it.

34. It also involves more funds and a more realistic way of transferring them from hospital to the community. Alternative accommodation and hospitals must be built before wards are closed and hospitals run down. This may involve double funding to fill the gap and substantial bridging loans. (See Gillian Shephard's Adjournement Debate, Hansard 1 February 1989.)

LOCAL AUTHORITY CARE

35. Although welcoming many of Griffiths proposals, I am personally alarmed at relying on local authorities with their competing demands to provide continuing care for people who are seriously mentally ill. Experience has shown that child abuse, care of the physically disabled and almost every other need takes priority over chronic mental illness.

36. Schizophrenia is a complex and frightening condition which needs skill and experience in handling. Unlike someone suffering from a permanent disability or mental handicap, the schizophrenia sufferer may be rational one moment but irrational the next. In fragmenting the care into small units all over the community there is a danger that the quality of staff will be diminished. And that without supervision, inexperienced people in charge of say 5 or 6 disturbed ex patients may not be able to cope.

37. Even places I have visited which have been put forward as models of community care have been obviously inadequate. The care plans my look good on paper but in practice mean little. A place in a day centre may mean only one afternoon session a week. But there is nowhere for the ex-patient to go at weekends and what happens when he becomes ill and withdrawn and fails to turn up?

38. Similarly, group homes or hostels may provide inadequate monitoring. One house I visited in North London for 6 ex-patients from Friern Hospital was run by the wife of an builder. They had taken out a second mortgage on the house and she came once a day to cook the evening meal at 3.00pm to fit in with her children's school times. Upstairs a girl in her 20s spent two years of her life in bed with a coat over her head.

PRIVATE SECTOR CARE

39. Accommodation in the private sector can be even less supportive. There are bed and breakfasts where ex-patients are encouraged to leave for the day and walk the streets. Untrained landladies are left to give out medication and cope with deluded and suicidal people. In some unsafe inner city areas such as Liverpool 8 or near busy roads, ex patients are locked into their homes for their own safety. Their lives are far more restricted than in a hospital ward.

40. I have also visited some extremely rough and unsavoury lodgings to which patients have been discharged from hospital or where they drift when evicted from "model" flats, group homes or hostels when their behaviour has been too difficult to contain. (Lorraine Lazarus from the film "Whose Mind Is It" was driven by social workers to a guest house where the caretaker did not speak English and no-one was aware she was 7 months pregnant and seriously mentally ill.)

41. Clearly, there should be much stricter monitoring of private sector care and better access to hospital support.

42. Schizophrenia is not a handicap but an illness (even though we do not yet know how to cure it) and should remain the responsibility of the health authority.

EDUCATION AND TRAINING

43. There is a need for reorientation of attitudes, especially among social workers. We must not be overtaken by the philosophy of independence at all costs. All too often independence means neglect for the patient and torment for the family. We should accept that a proportion of people with mental illness will need continuing hospital care. Many social workers are trained, in my view wrongly, to regard intervention as only successful if it avoids hospital admission.

44. Existing provisions in the Mental Health Act are often not implemented for ideological reasons. For example, doctors wishing to have a disturbed patient admitted to hospital involuntarily must get the agreement of an authorised social worker, many of whom have had little experience and are very much concerned about patients' rights. I believe that social workers, GPs, psychiatrists and others within the community, such as police and magistrates, who are likely to have to deal with schizophrenia should receive co-ordinated training. There should be stronger leadership from psychiatrists and guidelines from government.

INVOLVING THE FAMILY

45. Finally, where families are caring for a sufferer, their views should be taken into account. Often they are most aware of an incipient relapse, yet the emphasis on the patient often leaves them unheard and unsupported. If included and given adequate help, families could be tapped as a major resource.

46. For this to work there must be 24 hour availability of skilled advice and easier access to hospital care or "refuge" in times of crisis.

47. There should also be means of intervening before the situation has become intolerable. Most families I have spoken to say the police are the only people prepared to help when they feel there is danger. But even then the police cannot intervene unless they can persuade the sufferer to go into the street and cause a public nuisance there. The last recourse is through the law and parents are being advised to take out injunctions against their own children to prevent them returning home or are advised to move house and keep their address secret.

THE RIGHT TO CARE AND TREATMENT.

48. More choice should be given to patients themselves to be cared for in or out of hospital. I have come across several stories where a person has begged not to be discharged or to be admitted to hospital but told that there are no beds either because the hospital is being run-down or because he is not an acute treatable case. Sometimes patients are told that it is "good for them" to go into the community and struggle to maintain sanity in a flat or bed and breakfast. Their only way back into care is to throw a brick through a window or commit some petty crime.

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BRITISH MEDICAL ASSOCIATION

Prime Minister
A thoroughly ostrich like response. No chance is preparing a riposte
AT 2/3

2 March 1989

NHS REVIEW - BMA COUNCIL RESOLUTIONS

(1) The BMA Council is convinced that many of the proposals contained in the NHS Review "Working for Patients" will cause serious damage to patient care within the NHS.

(2) The proposals will lead to a fragmented service and will destroy the comprehensive nature of the existing NHS.

(3) The proposals ignore the critical issue of inadequate funding of the NHS.

(4) The Review claims that the proposals will increase patient choice. The Council is convinced that they will limit it.

(5) The information systems necessary to implement the proposals in the Review are still in an experimental stage and will take years to develop at considerable expense. This development must be separately funded by the Government.

(6) The refusal of the Government to allow the proposals to be evaluated by pilot schemes will lead to further problems and expense.

(7) The Council welcomes the Government's objectives to work with those providing the service to improve standards of patient care as set out in paragraph 2.11 of the Review*. It particularly welcomes the Government's recognition of the importance of medical audit.

(8) The Council is pleased to note the Government's statement that it is doctors, not politicians or managers, who treat patients (paragraph 10.11), but very much regrets that no steps were taken to discuss the proposals with representatives of the profession before they were published.

(9) The Council will take steps to inform the public, press and Parliament of its serious concern at the consequences that many of the proposals will have for the health of the nation.

*Paragraph 2.11 reads: The Government's objective is to create an organisation in which those who are actually providing the services are also responsible for day-to-day decisions about operational matters. Like RHAs, DHAs can then concentrate on ensuring that the health needs of the population for which they are responsible are met; that there are

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Secretary J D J Havard MA MD LLM

effective services for the prevention and control of diseases and the promotion of health; that their population has access to a comprehensive range of high quality, value for money services; and on setting targets for and monitoring the performance of those management units for which they continue to have responsibility. The Government will expect authorities to provide themselves with the medical and nursing advice they will need if they are to undertake these tasks effectively.

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