



PRIME MINISTER

COMMUNITY CARE

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I agreed at our meeting on 21 March to circulate a note on the way we have gone about the development of community care in Wales. I believe our experience provides important pointers to the right way forward, not least because it is based on the approach we agreed at our meeting that we should aim to avoid creating new agencies, ensure better co-ordination of those which already exist, and build on the merits of the present system, while overcoming its weaknesses.

In 1983 my predecessor launched the all-Wales strategy for the development of mental handicap services. This followed detailed analysis of the issues by a working party of key interest, including representatives of the voluntary sector and users of services. At that time there were an estimated 10,000 people in Wales with severe mental handicaps. Fully 8,000 or so of those were living at home, supported by their families who were receiving very little help from anyone else. Social services and community health expenditure at that time totalled no more than about £8m per annum. Most of this was not providing direct support for families, but traditional long-term residential hostels and poorly funded, unimaginative adult training centres which failed to provide the stimulation people with mental handicaps need to reach their full potential. By contrast, some 2,200 people, with a range and degree of handicaps generally no greater than those living with their families, were being cared for in hospitals, the great majority in 4 large, traditional institutions. Although conditions in the hospitals were poor and depressing, fully £25m per annum was being spent on them.

It was quite clear that this imbalance of provision was self-perpetuating. Poor quality support for families meant that when they were no longer able or willing to cope, as they became older or as parents died, there was rarely any other choice but for the person with the mental handicap to go into expensive but inappropriate institutional care. The main challenge, therefore, was to build up new patterns of services in communities, with an emphasis on direct support to families and the development of the capacity of the people with handicaps themselves, for example through providing opportunities for them to live in their own homes. In parallel, the strategy sought to improve conditions in the hospitals, but emphasised the importance of equal access to the new patterns of services for those currently in institutions. No arbitrary timetable was set in advance for the run-down or closure of existing institutions: that was to be determined in the light of success in developing the new patterns of services.

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Obviously, it was not sufficient simply to state these radical objectives: there had to be effective means to achieve them. Taking advantage of the absence of a regional tier of health authorities and the Welsh Office's direct lines of communication with our 9 health authorities and 8 social services departments (co-terminous in all but one case), the authorities were required to work together and in close co-operation with the voluntary sector and users of service, to plan jointly for the development and delivery of the new services. Since the needs of people with mental handicaps and their families are overwhelmingly social rather than medical, the social services authorities were asked to co-ordinate this effort.

It was clear that progress could not be secured without the injection of direct payments by the Welsh Office to help meet the costs (some of which would be transitional, some long-term) of building up the new services, at the same time as the traditional institutions had to be maintained. The direct payments enabled the Welsh Office to make sure that everyone faced up to their responsibilities, that the joint planning was effective and that the best use was made of the total resources available.

Six years on, the strategy has proved remarkably successful and popular, and is the subject of favourable attention, not only throughout the United Kingdom but internationally as well. The number of families receiving direct support in their own homes has risen from 41 in 1982/83 to 1,858 in 1987/88; the number of places available for people with mental handicaps to receive regular short-term care has risen from 34 to 404; the number living in their own homes from 166 to 614; and the number receiving fully acceptable day care services from 37 to 809. At the same time, the resident specialist hospital and hostel population fell from 2,089 in 1983 to 1,692 in 1987, a reduction of 19%. More significantly still, the total number of admissions to these hospitals and hostels has fallen from a peak of 2,059 in 1985 to 1,630 in 1987 and is coming down sharply. This is particularly important because it is contrary to the trend in England (and I believe elsewhere in the UK) where numbers of admissions have continued to rise, as hospitals are being used increasingly for short-term care. By contrast, in Wales this care is being provided through direct support for families and arrangements for community-based respite care, often provided by a highly efficient voluntary sector, such as Barnardo's which arranges a regular substitute family for the period of care.

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Direct Welsh Office expenditure on the strategy was £10m in 1987/88 and £13.75m in 1988/89. But already by 1987/88 £4m of expenditure by health and social services authorities had been redeployed on the new patterns of services; and the social services authorities were, compared with 1982/83, investing from their own resources an additional £2.37m in real terms. Crucially, this redeployment is now planned to accelerate markedly, as experience in developing the new patterns of services enables all concerned to effect the substantial run-down and eventual closure of outmoded forms of care, in a way which enhances the quality of care provided for individuals and their families.

In May 1988 I published for public consultation a parallel strategy for mental illness services. This has received general acclaim and I am publishing the final version next month. It too exploits our short lines of communication and close relationship with the authorities and other interests, to require effective joint working in each county area.

In this sphere too, despite considerable investment to improve conditions over the past decade, we are far too reliant on an inheritance of large Victorian and Edwardian hospitals, which are often remote and in poor physical condition. Even if there were no change in current patterns of care, they would require considerable investment to maintain. The key issue is to facilitate the humane transition to a much more decentralised pattern of services. Unlike the case for those with mental handicaps, many of those with mental illnesses require regular clinical care and supervision, so the NHS, both through hospital and community services, will continue to provide the lion's share of what is needed. But social support needs to be developed too for those who can and wish to live in their own communities. And we must be wary of too simplistic a view of this issue. For most people suffering from mental illnesses, (including those with long-term schizophrenia) the choice should not be the stark one between hospital or community care, but rather access to a range of services which can meet their particular needs at any one time, since symptoms and circumstances can change significantly. This is not least true of those who are elderly and suffer from dementia (perhaps 20% of those over 80) most of whom can be cared for at home for long periods, provided their families receive tailored support which prevents these arrangements from breaking down.

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Once again, the move to this desirable new pattern of services requires transitional funding, and probably some longer-term uplift too since, by common consent, these services have always been under-funded and conditions in the hospitals are often still very poor. But I have reserved judgement on what investment I might be prepared to make until I see the fruits of the joint planning which the strategy calls for, since I am determined to ensure that the best use is made of the considerable total resources available for these services. We estimate these to have been some £110m in 1987 (this includes estimated expenditure by general medical practitioners).

We have had to develop these distinctive strategies in Wales against the background, which concerns us all, of uncontrolled expansion of private residential and nursing home care through access to income support. Indeed, these income support payments probably represent the preponderance of expenditure on care of the elderly and of those with mental handicaps or mental illnesses in Wales. In respect of elderly people (apart from those with mental illnesses) constraints on the expenditure which I control directly has meant that my ability to secure a more sensible use of total resources has been limited to a nonetheless important initiative to foster and disseminate good practice through pilot projects.

What that initiative and our fully fledged strategies show clearly is that effective joint planning between all those with a part to play has to be at the heart of efforts to support families and those who need care in their own homes and communities, including residential care where that is what they need and wish. As we noted in our discussion, there is no way in which sufficient resources can be made available by central government or from other public sources to meet all care needs, and neither is that desirable since the overwhelming majority of people in need and their families want to do as much as they can for themselves. But more often than not they need limited direct support from health, social services or the voluntary sector if those arrangements for informal care are not to break down, leaving the state to pick up a much bigger share of responsibility and a correspondingly bigger bill.

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These considerations, and the importance of a flexible response which can meet the changing needs of individuals over time, point unequivocally, in my view, to the need to end access to income support for the care element of residential and nursing home fees. As we agreed, we want to end notions of entitlement to finance for care. To achieve that, we need a system which enables priorities to be established locally so that care and support can be delivered to those who need it most. Introducing assessments before income support is payable will not achieve this. The health and social services authorities would continue to have an incentive to run down their own services and to refer people for assessment. Moreover, many people and their families may need some limited support short of residential or nursing home care, so a system of assessment determining entitlement to income support for residential or nursing home care alone would be too black and white. As I have said, needs change over time and we must avoid building in inflexibilities and distortions which prevent a response sensitive to people's real needs. Paying income support at higher levels on a basis which did not discriminate between residential and domiciliary care would have massive expenditure implications, including a substantial 'dead-weight' of people who would not otherwise make significant demands on public expenditure.

I believe that the arrangements I am piloting in Wales in the field of mental handicap and now extended to mental illness are the best way forward, particularly if we build on that approach a developing regime of competitive tendering for the provision of services. This would enable the private sector to diversify from its present concentration on residential and nursing home care into the provision of domiciliary services tailored to individual needs. This approach avoids organisational change and the political difficulties we have identified. It would give us the means to prevent the uncontrolled growth of public expenditure, end the unacceptable system of entitlement to state support for care, and ensure that, by transferring the resources which are provided to the main health and social services programmes, they are spent on those with the greatest needs.

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I would like to make just two other points arising from our discussion. First, I can see the immediate attraction of developing personal and family responsibility by providing tax relief for those who provide care. But we would ignore at our peril the fact that many of those providing informal care are poor (often as a direct result of their inability, because of their caring role, to take a full-time job or to advance in the job they have) and they would not be helped significantly by such a move. Second, I agree fully about the crucial importance of developing a role of the voluntary sector in community care. That has been a major feature of our all-Wales mental handicap strategy and is a strong theme of the new mental illness strategy. However, certainly in Wales the voluntary sector is insufficiently strong to make the lion's share of the contribution to services which is needed. Like it or not, we shall have to rely for that on the health and social services authorities, but with an increasing role for the private as well as the voluntary sector.

/ I am copying this to Nicholas Ridley, Malcolm Rifkind, Kenneth Clarke, John Moore, John Major, David Mellor, Sir Robin Butler, Sir Roy Griffiths, Mr Wilson and Mr Monger (Cabinet Office) and Mr Whitehead (Policy Unit)

7 April 1989

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