Making progress—community care in Northern Ireland

Alison Tonks

This is the sixth in a series of articles looking at the forthcoming changes to community care

The community care reforms that will be implemented throughout the United Kingdom from 1 April depend on close cooperation between health and social services. Sceptics have suggested that differences in the training and philosophy of those in the two services might lead to difficult culture clashes. In Northern Ireland, however, health and social services have been integrated for 20 years and this may give the province a head start in coping with the reforms.

Until two years ago the two branches had separate professional lines of management, but since 1990 services have been united all the way down from administrators in the Department of Health and Social Services to the professionals providing care. Local authorities, which have responsibility for social services in the rest of the United Kingdom, do exist in Ulster, but they deal exclusively with municipal and environmental health tasks such as emptying dustbins and cleaning the streets.

The organisational hierarchy has only three tiers. At the top is the Department of Health and Social Services. Below this are the province's four health and social services boards: northern, southern, eastern, and western. The boards are split up further into units of management; administrative areas that contain varying numbers of hospitals, health centres, and other providers of community services. The Eastern Health and Social Services Board has nine units of management. Four of them are community units, although within this, they may manage a small acute hospital. Some hospitals, such as the Belfast City Hospital, are units of management on their own.

Planning community care with an integrated service

During a visit to Northern Ireland I spoke to Margaret Bamford, assistant director of social services at the Eastern board, and Bob Moore, the board's social services director. They both agree that integration has helped the planning of community care. Firstly, local authorities and health authorities don't have to make special efforts to get together to make plans. Secondly, the transfer of funding between health and local authorities that has proved so difficult in other parts of Britain is unnecessary in Northern Ireland. Finally, integration makes it easier for professionals and managers from each side to talk to each other and begin to bridge the cultural divide between them.

Bob Moore insisted that integration was not a panacea for the potential woes of community care. "Because of integration our units of management haven't been able to become NHS trusts. At the moment there is no legal framework allowing social services to be trusts. Our units of management will have to wait for enabling legislation to go through before they can become trusts in 1994." Margaret Bamford also added a cautionary note: "Integration is far more evident at senior management level than at the grass roots. The nearer to the patients you get, the greater the divide," she said.

Rene Boyd, retired social worker and former assistant director of social services, agreed that social workers and health workers still speak different languages. "When a social worker asks if a patient can walk she means, 'Can that patient walk well enough to go home?' When doctors talk about a patient walking they mean anything from trotting up hills to taking a few steps heavily supported by four people."

Cultural differences

The cultural and demographic differences that separate Northern Ireland from the rest of Britain work both ways for the health and social wellbeing of the people who live here. Disability in general is commoner and the prevalence of coronary heart disease is higher. Data from Northern Ireland's Policy Planning and Research Unit show that the incidence of disability among adults is 174/1000, and that 20/1000 are severely disabled. About 17% of the total population has some form of disability.

On the other hand, the closeness of the community and strong family ties means fewer homeless young people on the streets of Belfast. "Young people here always have somewhere to go, either to family or friends," says Dr Raymond Shearer, a general practitioner in Crocus Street, near to the troubled centre of Belfast. "Homelessness isn't non-existent, but it is nothing like as bad as in some English cities."

A strong sense of spiritual identity and loyalty within families also means that there is a social network of support from family, friends, neighbours, and the church. Many people I spoke to mentioned the willingness of the Northern Irish to care for their elderly and disabled relatives at home, sometimes with minimal help. "I am constantly humbled by the decency of the folk out there," says Dr Shearer. "Some of the young people in particular are very generous with their time."

Planning community care in the Eastern Board

The Eastern Health and Social Services Board is the biggest of the four boards. About 635 000 people live within its area; 44% of the population of Northern Ireland. It covers an area extending from North Belfast to the Mourne mountains in the south and includes most of the city of Belfast. The city is fairly small, with a population of less than 400 000, about the same as Bristol. There are only 1·5 million people living in the whole province.

Belfast's teaching hospitals and tertiary referral centres all fall within the eastern board's remit. Until now the city attracted the largest slice of the funding cake from the Department of Health and Social Services. From 1 April, however, this board's directors will have to deal not only with new funding arrangements for community care but also with a considerable loss of revenue because its specialist centres and teaching hospitals will not attract any extra money. Funding will be calculated on a per capita basis for each board, regardless of the facilities available in each. The end of preferential funding for the Eastern board means that it will have to implement the community care changes with a total budget reduced by £51m.

Despite this setback to the board's finances, Bob Moore and Margaret Bamford are confident that all the

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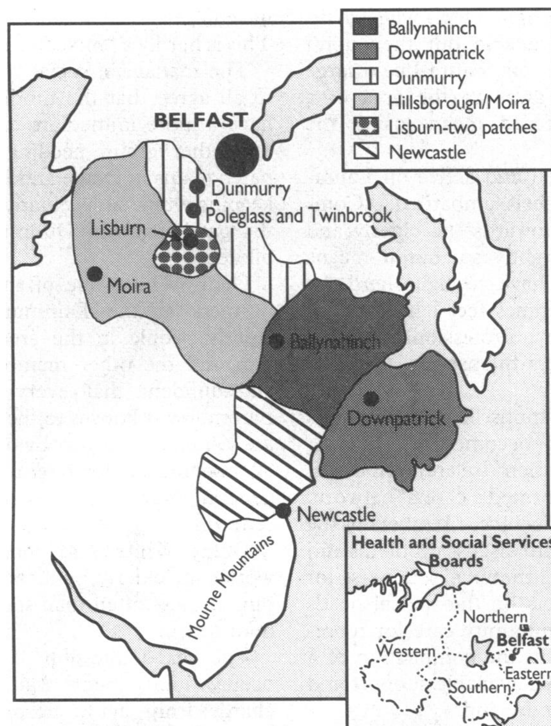


Patches in the eastern board's Down and Lisburn unit of management. Patches are based around general practises and each has an integrated primary care team

operational structures needed to cope with the new arrangements will be in place by April. They both agree with the principles behind the NHS and Community Care Act 1990 and the policy paper that detailed the reforms in Northern Ireland, *People First.*[1]

Bob Moore has certain reservations about putting the theory into practice. "The needs led approach is ideologically sound," he said, "but it's possible that its implementation could be paralysed because of lack of funding. The whole of Northern Ireland is getting only £4m extra to set up the new funding arrangements. I don't think it will be enough. The government is trying to get community care on the cheap and that will mean only one thing—rationing." He is also concerned that the board could end up being taken to court if the funds were not available to meet a client's assessed needs.

Margaret Bamford also has reservations. "The Department of Health and Social Services has set a target that, by 1997, fewer than 12% of the over 75s should be in institutional care. That figure at the moment stands at 16-22%. This means that if we meet the target some residential and nursing homes may well go out of business; a very grave prospect in the current gloomy economic climate."

A working group, chaired by Margaret Bamford and including representatives from the units of general management, has written a detailed draft document outlining the process of care management. The final draft will form the basis for contracts between the board and the units of management that will provide the care through their hospitals, health centres, community health services, statutory social services (for example, the provision of home helps), and residential homes for elderly people. The units of management will also be given a budget to purchase a "mixed economy" of social care from the voluntary and private sector.

Down and Lisburn unit covers half the area of the eastern board and serves a quarter of its population. The area is diverse: some of the richest and some of the poorest people in the province come under the unit's remit. It covers the deprived areas of Poleglass and Twinbrook that spill out of west Belfast, the privileged commuter belt, and the scattered rural communities that spread out towards the Mourne mountains in the south.

Brian Dornan, an assistant unit general manager, explained that in anticipation of the changes to community care Down and Lisburn unit had been divided into "patches." Each patch is based around a general practice and has a patch team. The patch teams—or integrated care teams—include a general practitioner, community health professionals, and social workers. For example, the patch team in Dunmurry is based around a general practice with four partners. The team is made up of three district nurses, a nursing auxiliary, a midwife, two health visitors, a part time social worker, and a social work assistant.

Each of the unit's six patches has a patch manager and an assistant patch manager. One is a nurse and one a social worker. The patch arrangement was successfully piloted in Dunmurry at the beginning of last year and has been fully operational for five months. Detailed plans for assessment and care management have been drawn up, so that when open access to residential and nursing homes for the elderly ends, there will be someone on the spot who knows how to get the assessment procedures going. That person will be the patch manager. Eventually, patch managers will take over the budget for care management.

Brian Dornan is highly committed to the patch model. He believes that patch teams should be well placed to cope with the biggest change in April—care of frail elderly people. Arrangements for other groups of disabled people are still evolving in unit wide programmes. Like everyone else at the planning end, Brian Dornan is concerned about funding. The changes will mean new employees such as accountants, who will have to be paid. Exactly how much money there will be and who will get it is yet to be worked out.

The carers

There are an estimated 210 000 carers in Northern Ireland according to the Carers National Association. Without them current government policy would be a nonsense. They are unpaid and, as Dr Shearer pointed out, largely uncomplaining. Bill Love, the Northern Ireland development worker for Carers National Association, is guardedly optimistic. "On paper the changes look good for carers," he said, "but as always there are funding constraints."

Patricia Jenkins has been caring for her disabled daughter for seven years. She knows all about funding constraints. Laura-Lee was 2 when she developed a spinal tumour—an ependymoma—and she is now paraplegic and dependent on a wheelchair. Caring for her is a full time job.

Mrs Jenkins' marriage has broken up because, as she puts it, "there's just no room for a marriage when you're caring for someone else all the time." She also suffers from social isolation. Laura-Lee is growing up and her mother is finding it increasingly difficult to lift her into the car to go out. Her disease is so rare that there is no local group for sufferers: support groups tend to be disease specific, and Laura-Lee cannot attend groups for sufferers of spina bifida or cerebral palsy. Local respite care facilities are unsuitable because they tend to be for children with learning disabilities, so Mrs Jenkins has not had a weekend away since Laura-Lee was born. Laura-Lee was once offered respite care in England but her mother couldn't afford the plane fare.

A home help comes in for five hours a week to help with cleaning, and a social worker visits whenever something needs sorting out. Input from the voluntary services is minimal. Housing is one of the Jenkins' biggest worries. Their small three bedroomed council

house is adequate but is not designed for a wheelchair. Wheelchair bungalows are available but they don't have adequate storage space for Laura-Lee's large mobility aids. Also, moving away to the area of a new unit of management could mean losing the home help.

Mrs Jenkins is well informed and active on Laura-Lee's behalf. But she often feels embattled. "Community care is really geared towards the elderly and mentally handicapped, and rightly so, but it means with a child like mine you have to fight hard for everything," she says. I sometimes feel I have to act like a barrister or even a spy. Professionals should listen much more to the carers themselves. Only we know what it's really like."

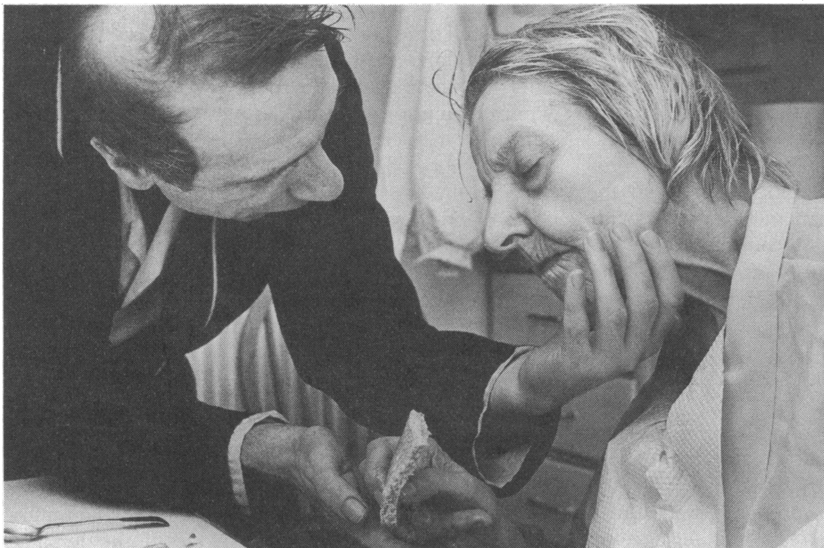
The good news is that situations like Mrs Jenkins' should improve as agencies become more "carer aware." To this ¨nd, 11 of Northern Ireland's 18 carers groups and associations have formed a carers' network, representing all carers in the province. Members of the network meet four times a year to discuss problems and plan strategy. Plans include training seminars for nurses and general practitioners on the special needs of carers, a conference on community care for representatives from the church, and the compilation of a carers' directory detailing all the available support and resources for carers in Northern Ireland.

Also in the pipeline are two pilot projects—one rural, one urban—which are jointly funded by the eastern and southern boards and the Princess Royal Trust for Carers. The urban project in north Belfast involves eight diverse organisations across the voluntary and statutory sectors working together to provide coordinated help and support. Improving respite care, providing training for carers, and expanding the network of local support groups are all on the agenda.

So far, so good. Bill Love's main worry is that, after April, complex or poorly managed assessment procedures could mean that carers have to wait longer for vital help. He also fears that, because of limited cash, carers could end up paying for services like home helps and respite care or even losing services altogether.

Keeping elderly people at home

Around a fifth of people over 75 live in some form of institution in Northern Ireland. Statutory beds—those run by the health and social services boards—are in the minority. Three quarters of residential home places are privately owned, as are all nursing homes. This means that elderly people who do need a nursing home place have little choice about what sort of home they live in. This is hardly a "mixed economy" of care.



SAM TANNER

Unpaid informal carers are the heroes of the government's community care policy

The managers, social workers, and doctors I spoke to all agree that the funding changes on 1 April will have a more immediate effect on the elderly than on any other group needing community support. The patch teams in Down and Lisburn play a central role in keeping vulnerable elderly people at home. I visited the patch team in Dunmurry, where the model was piloted.

Denis White, one of the four general practitioner partners at the Dunmurry practice, believes that elderly people in the area get a good service from him and the other members of the team. They are all confident that every vulnerable old person in Dunmurry is known to the practice: all people over 75 are visited once a year by one of the district nurses and all patients on long term medication are seen by a general practitioner each time prescriptions need renewing.

Denis White said that, far from increasing his workload, elderly patients in their own homes called him out less often than staff in residential and nursing homes.

The vexed question of whether bed blocking will occur while patients wait for assessment before discharge from acute hospitals will probably not be answered until April, when assessment before discharge becomes compulsory. Margaret Bamford, thinks that a degree of bed blocking is almost inevitable. Mary McBrien, principal social worker for the north and west unit of management, is more optimistic. "Discharging vulnerable elderly people from acute geriatric wards shouldn't be much of a problem because geriatricians are used to multidisciplinary assessment before discharge," she said. "The real problem will be with other specialists like orthopaedic surgeons, who are much more in the dark about assessment."

The closure of long stay geriatric beds has released funds that have been used to set up a number of community support schemes for the elderly. Money in Northern Ireland finds its way relatively easily from the closure of long stay beds into the community. The Department of Health and Social Services provides bridging loans to community projects to tide them over until the beds have been closed and the money is available.

For example, Dr White's patients have access to an intensive domicilliary support scheme. There are five such schemes currently up and running in the eastern board's area. Places on the scheme are offered to elderly people with complex needs who have had full multidisciplinary assessments. They are intended for people who would otherwise have to live in residential or nursing homes.

The Down and Lisburn scheme employs 15 full time equivalent care attendants. They visit clients as often as necessary and can help with almost anything: getting out of bed, dressing, bathing, cleaning, shopping, or lighting a fire. Schemes can also buy in other services from the voluntary or private sector. For example, Down and Lisburn's scheme sometimes uses the voluntary organisation Extra Care to provide night cover. Joe Dunne, Down and Lisburn's programme manager for the elderly, is confident that the scheme will be able to expand after April. At the moment there are 15 places.

Services for mentally infirm elderly people

The most vulnerable group of all are the sufferers from dementia. The closure of a ward in Lisburn's long stay psychiatric hospital, Downshire, has freed money to set up a multidisciplinary dementia team based in a

health centre in rural Ballynahinch. The team has a manager, a consultant psychogeriatrician, two community psychiatric nurses, two social workers, and an occupational therapist. The team takes referrals from anywhere in the Down and Lisburn unit of management, and from anyone. Friends, relatives, general practitioners, geriatricians, or worried home helps can pick up the phone and ask for help or advice.

The project has been running for five months. It is purpose built for the government's community care policy: easily accessible, flexible, carer friendly, and keen to use as many different agencies as possible. They are already busy. One of the community psychiatric nurses has a case load of 60 clients and expects more referrals when care management gets under way.

Community schemes like these are tangible evidence that, with adequate funding and collaboration between health and social services, community care policy can really progress. There seems to be less danger in Northern Ireland than in the rest of the United Kingdom that vulnerable elderly people will get caught in the crossfire between health and social service authorities arguing over who funds what.

Chronic mental illness in younger people

Downshire Hospital is one of six long stay psychiatric hospitals in the province. The process of settling inpatients in the community is well under way. An integrated mental health programme and the availability of bridging finance has helped the resettlement process. Anyone discharged from the hospital has a care plan and a key worker, usually a community psychiatric nurse or a social worker. The key worker meets with the patient's psychiatrist weekly after discharge, which means that patients are very rarely lost to follow up.

Rosemary Simpson, Down and Lisburn's programme manager for mental health, explained that a recent survey identified all but one of the patients who had been discharged from Downshire Hospital over the past 10 years. Rosemary Simpson does not anticipate any major upheavals in April and expects the programme to carry on as before. They have plans to build a small "village" of houses for discharged patients within the grounds of the hospital.

Services for people with learning disabilities

Muckamore Abbey is the Eastern Health and Social Services Board's hospital for people with learning disabilities. The biggest of three such hospitals in the province, it was built in the 1950s and over the years has had varying numbers of inpatients. Dr Caroline Marriot, a consultant psychiatrist based at the hospital, estimates that there are currently about 500 inpatients. The hospital has an active resettlement programme. Since 1987 over 200 inpatients have been discharged.

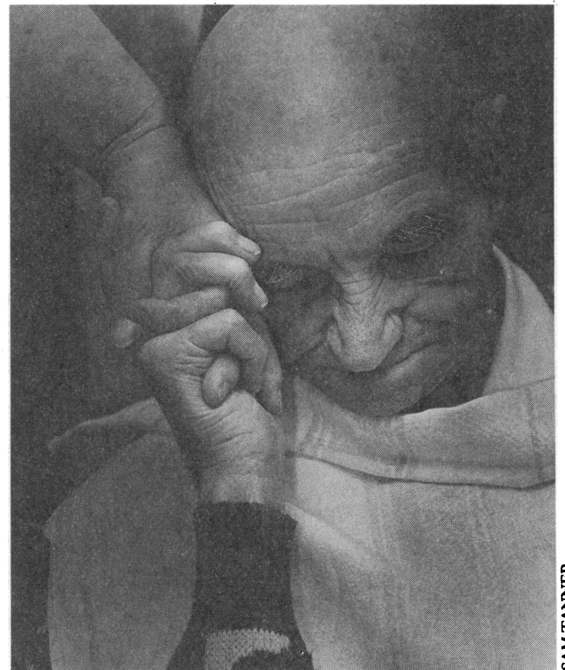
Historically, says Dr Marriot, Northern Ireland has always had a more emancipated policy for people with learning disabilities than have other parts of Great Britain. In the 1940s the special care service for people with learning disabilities began. Among other things, the service established a register for the whole province. By the 1960s hostels in the community were already looking after less disabled people, so care in the community is very much the tradition here.

Dr Marriot estimates that over 70% of adults and children with learning disabilities are looked after at home. If a child is born with a learning disability and the parents are unable to cope then the baby stays in hospital until a foster family can be found.

For people needing care away from home there are a variety of different residential services. Most of the inpatients discharged from Muckamore Abbey in the past three years have gone to privately owned nursing homes. So called "core and cluster" facilities are available for less disabled people. For example, Hillhall Home in Lisburn is a modern terrace of houses which has accommodation for 16 people. This core unit is staffed but includes a three bedroomed self contained house for semi independent living. Another 11 people live independently on the same housing estate but with support from residential home staff close by.

"Most of the community services have always been social services led," said Dr Marriot, "but, because of our integrated health and social services, there is close contact with the paramedical professions like clinical psychologists, community psychiatric nurses, and speech therapists. In theory it should be easy to access these services but in practice it's much more difficult. We have over 100 patients still in Muckamore Abbey who could leave tomorrow if the facilities were there for them to go to."

Multidisciplinary assessment and care plans are not new ideas to professionals working with people with learning disabilities. Dr Marriot believes that their best practice fits in largely with government policy on community care. She is unsure what to expect from the implementation of care management but, like many others, does not expect the earth to move in April.



SAM TANNER

The funding changes in April will affect vulnerable elderly people more than any other group

Conclusion

Everyone I spoke to was completely committed to the principles laid down in the NHS and Community Care Act. Many of the managers were optimistic, whereas the providers—doctors in particular—were uncertain about exactly what was going to happen.

The amount of funding was a recurring theme and rationing came up in almost every conversation. Nevertheless, the eastern board, at least, seems to have a solid foundation for the changes. Interdisciplinary teams are well established, managers and professionals seem to get on well, and nobody is short of ideas for what to do with any additional funding.

1 Secretary of State for Northern Ireland. *People first: community care in Northern Ireland in the 1990s.* London: HMSO, 1990.