away from the learning disabled to other care groups. For parents in their 70s and 80s, still caring for their often very disabled offspring, this can only make matters worse. Without a funding package of a new order of magnitude, their outlook, along with that of school leavers with learning disabilities, will be increasingly bleak.

We thank Charles Kennedy MP and Dr Tad Baecker for their help in this study.

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Countdown to Community Care

Helping disabled people—the user's view

Peter Swain

This is one of a series of articles looking at the changes to community care

The main needs for most people with physical disabilities are housing and help with daily living. Thus, many of them will find the new emphasis on social aspects of community care particularly relevant. Peter Swain is a disabled man who leads a project in east Devon which ensures that disabled people have a voice in helping to shape the services they need. In this article he explains how the project, Living Options East Devon, works and how the new legislation for community care might affect disabled people.

All disabled people would get a good deal if unlimited funding were available for community care. They would have individual assessments of need to identify care packages and equipment required for independent living. Care managers would have the satisfaction of working in a system that allowed them to solve problems and use the skills they had learnt during training. Until recently, the strong Swedish and Danish social welfare systems offered such services with few cost constraints.¹

But our new world of community care is cash limited. Clearly, priorities will have to be set and only the most pressing needs will be met. People with physical disabilities have certain key priorities for care (see box), the most basic of which is somewhere to live.

Priorities for disabled people

- Somewhere to live
- Appropriate care services
- Mobility
- Access
- Opportunity

Special housing

Without suitable housing, community care for disabled people is doomed to failure. But the government's initial publications on the reforms did not mention housing. Subsequent documents highlighted the need for and lack of adequate "special needs" provision. New building programmes for disabled people have been reduced substantially² and the availability of suitable rented accommodation was decimated in the 1980s by the policy that gave council tenants the right to buy their homes.

The lack of housing is lamentable, given the growing numbers of people who have long life expectancy but severe disability after surviving accidents. There are also many more young people who now hope to live independently in the community, rather than in institutions or their parents' homes, after passing through special education. Expectations are growing constantly and packages of care must begin to match them.

Care packages

There is nothing new about care packages. They have been used for years by a few disabled people, but often at huge cost.³ The concept of care management is not new, either. A similar job has been done for years by good home care organisers who know their patches and can mobilise swiftly a range of services to meet a variety of needs. The reforms simply identify and formalise this role.

Clearly identified care managers could make the process of referral relatively straightforward, predictable, and quick. Effective referral should take into account clients' views on services, and this will depend on good, up to date information on what is available so that clients can make informed choices. Social services departments must ensure that such information is readily available. They must also decide on realistic minimum standards and time intervals for responding to referrals, setting up assessments, and initiating packages of care.

Assessment should be a joint exercise, with disabled people and, when appropriate, their carers participating. They will be in the best position to ensure that their other essential needs—access, mobility, and opportunity—are provided for along with housing and domiciliary support. These "value added" factors open the way to further and higher education, employment, personal relationships, and all those other things that contribute to an acceptable quality of life. Ignoring these factors during assessment would reduce considerably the potential benefits of the new system and would leave many disabled people unfulfilled and unnecessarily limited.

Thus, good holistic care management could help the overall development of disabled people's potential. Some people might want to act as their own care managers, although they would probably need training to acquire the skills needed to employ and organise teams of care staff.

As well as providing for clients' basic needs and potentials, care packages must be responsive, flexible, and reliable (see case study 1). Whenever possible a single agency should provide the bulk of care. This approach is less intrusive for clients, cheaper to provide, and less bureaucratic to administer than a multiagency package.⁴ When many services are provided, they must be coordinated properly—having staff stacking up at the door waiting to do the next job is almost as frustrating as having no one turn up.

Finally, what about the frustrations of the care

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Case study 1

Mrs A is a young woman with multiple sclerosis living with her teenage daughter in an adapted council bungalow. She uses a wheelchair. Her care package is provided by a private agency, social services, and health services.

Mrs A receives money from the Independent Living Fund, all of which she pays to the private agency that provides the bulk of her care. She has to supplement this cost from other sources, and also receives some help from the Multiple Sclerosis Society.

The private agency staff sleep in with Mrs A five nights a week, and Social services provide a home care assistant for two nights. The agency provides a carer for two hours each morning and for two hours in the afternoon at weekends. Social services provide a home care assistant for two hours every weekday afternoon. The district nurse calls once a morning on weekdays to help Mrs A to the toilet. "Perhaps they think I go into suspended animation for the rest of the time!"

Mrs A speaks very highly of the private agency, saying that it has never let her down and that she can even telephone in the middle of the night if she needs help. She feels the agency has taken particular trouble to match her carers to her individual needs and preferences, and is happy with the small team of staff who work for her.

She speaks less highly of the social services department, saying that she would prefer to be given the money equivalent of their input so that she could purchase all her care from one source. Social services does not seem to have the flexibility to match client and carer satisfactorily, and she is concerned that she has to adjust to different carers from week to week.

Mrs A regards the proprietor of the private agency as her care manager, although a part time social worker, one of the local home care managers, and the general practitioner are very much involved in her case. Case conferences are held at irregular intervals.

Sorting out a care package is "a free for all, you take the best you can," says Mrs A. "It really is a do it yourself job, and it is very difficult. I really had to be determined to get this package together. I can't remember who told me about the Independent Living Fund, perhaps it was the private agency. That was all processed fairly quickly. On the whole, I feel that social services and health will only do what they have to do, and no more."

managers? Who should care for them? Their jobs will often be stressful and they might benefit from a neutral forum in which to discuss their concerns and tensions.

Monitoring care

The new policy for community care assumes that huge numbers of agencies and individuals are ready to provide services. But this assumption may not yet be true in all parts of Britain. The number and range of services should be expanding because social services departments are now obliged to buy in 85% of services from the independent sector. The growth of the private sector will inevitably follow the supply of cash. Will purchasers be able to monitor and sustain the quality of private care?

Disabled users will be looking for safeguards against poor services and against packages that are driven by cost alone (see case study 2). Private and, for that matter, voluntary agencies offering care should be subject to regular and rigorous quality checks. They will have to set themselves minimum standards and expect scrutiny by independent inspectors. Users' groups should also help in auditing quality and customer satisfaction.

Complaints procedures are often inadequate. People are often loath to complain because they do not want to be ungrateful or do not have any faith in the likely

redress for poor service. At the very least users should be able to expect that providers who fail quality assurance checks will not be contracted with again.

The voluntary sector, that amorphous and uncoordinated mass of services and pressure groups, will also have to be monitored. And it will need to prepare itself to play a big part in what the community care gurus call "the mixed economy of care," acquiring skills in management, administration, and contracting to convince potential purchasers that the "goods" will be delivered on time.

The new arrangements will have a profound effect on the voluntary sector. A few voluntary organisations are very large and professional and are managed as well as, if not better than, their counterparts in the statutory health and social services. Most, however, are small and not well run. Those organisations that cannot respond to the new system's demands in imaginative and flexible ways may not survive. Those that can rise to the challenge will be a great asset to the provider network. But purchasers must resist the temptation to tamper with them and jeopardise the independence that makes them special.

Fitting together purchasers and providers from the various sectors can be very complicated. In east Devon a special coordinating agency, Living Options, acts as a link between agencies, sorts out the planning and delivery of care, and ensures that service users are right at the centre of the planning process.

Living Options—east Devon

East Devon is a relatively rural district stretching from Okehampton in the west to Axminster in the east, some 60 miles away. The district has quite a small population of about 300 000, mainly concentrated in Exeter, yet it has more than 150 voluntary groups for people with disabilities. Trying to pull these groups together to form a coherent consumer voice is a

Case study 2

G is a young man who has had multiple sclerosis for most of his adult life. After his mother died he went into residential care. After about two years he moved out into an adapted local authority bungalow with a complex care network to sustain him—this involved support from the voluntary organisation Crossroads, community nurses, home helps, and private agencies. He spent regular periods in local respite facilities for treatment and maintenance care.

In time the package became too difficult to maintain because of the intensity of care needed and because of G's deteriorating psychological condition. Extra care was bought from a private agency using money from the Independent Living Fund, supplemented by direct cash payments from the local home help budget.

The agency contracted to provide the care was new and was one of the cheapest locally, offering the highest number of care hours for the money available. One of its conditions of service was that no other agency could provide support.

All of G's affairs were conducted on his behalf by staff from the agency. They arranged his respite care and holidays, booking transport as necessary. But it soon became apparent that the transport was being arranged to suit the agency, with early morning departures and late evening returns. The transport service became suspicious of the agency's motives and eventually withdrew its vehicles. Further concerns arose when the agency asked social services to pay for a leather restraining harness for G so that he could be left alone safely, saving on care hours and costs.

At this point the voluntary organisation Living Options was called in by G's social worker. A case conference was held and the agency's input is being carefully monitored.

BRENDA PRINCE/FORMAT

Mobility, access, and opportunity are essential to develop an acceptable quality of life

daunting task. Many of them want to concentrate on their own sectional interests and many think parochially, looking to Exeter for guidance only reluctantly.

When we tried to establish Living Options as an informal confederation to represent disabled people the sceptics poured cold water on our plans. All too often, they said, voluntary organisations raise their heads over the parapet only to carp and criticise. Living Options set out to work in the boardroom, not at the barricades.

We have a clear vision of our aims and methods. And we fell into a fertile climate in which Exeter health authority had closed its institutions for mental illness and learning disability and had initiated high quality community services to replace them. Focusing on physically disabled people next was a logical step.

The Living Options project was launched in January 1990, funded mainly by the Nuffield Provincial Hospitals Trust. We were also helped greatly by an annual grant from the health authority, which paid for the hire of a suitable meeting room at a local hotel, travel expenses, and publication costs for reports.

Several years of planning and work before we started up had already produced a county wide federation of services that provide information on disability. In 1990 Living Options began a general survey of what services actually do. We also set up a subgroup of users and carers to work with the Disablement Services Centre in Exeter and help assimilate wheelchair services into the NHS.⁵ The local managers took up many of our recommendations and continue to collaborate with us about wheelchair services. And another district, seeing that we had solved a difficult problem, adopted our plan verbatim.

The subgroup went on to commission a three month trial of lightweight wheelchairs,⁶ which expanded the range issued by the disablement services centre and increased purchasers' flexibility. Now we are trying to develop the centre's range of equipment even further by espousing the voucher scheme recommended in the McColl report⁷ and to open a showroom where disabled people can be assessed for non-standard equipment. These early successes showed that Living Options could help users to participate in decision making as equal partners.

Subsequent work has focused on problems shown up by our first survey of services. Last year we pulled together the findings in a report, *Pathways to Quality*

Services,⁴ which is now being used by health and social services as a basis for planning and purchasing.

We have also undertaken more specialised work. In August 1991 we published a report on the needs of 100 people (16-65 years) with arthritis,⁸ which was taken up quickly by local planners. Another special report on people with sensory impairment will be published soon, and we have already linked with the district's audiology strategy group and among other things identified a shortfall in lip reading classes.

As well as drawing together information, Living Options is affecting local policy in two other ways—by acting as a watchdog and by taking part in planning at a high level. Firstly, we discovered a worrying lack of registration or monitoring of private care agencies, which could leave disabled people open to abuse. With two reputable private care employers and representatives from many interested agencies we drafted a voluntary code of practice which purchasers could use to accredit private providers. And some of our members have now joined the social services inspectorate to put together clear guidelines on accreditation. Finally, we are starting regular audit of randomly picked cases later this month to monitor customer satisfaction with community care policies.

When Living Options started up, various attempts had been made to revamp services for physical disability in east Devon without any real impact. Some new initiatives had been set up through individual effort with haphazard funding: inevitably they failed when initial finances were withdrawn or frozen. Exeter still lacked a cohesive plan for disability and managers in health and social services had little idea of what one might include. To resolve this a joint disability forum of senior managers from health, social services, and housing was set up. Living Options was invited to elect three representatives to sit on the forum and in 1991 the chairman of the Living Options Working Party was appointed chairman of the forum. Consumers were now clearly taking a leading role.

Conclusions

The main effect of the Living Options project in east Devon has been effective collaboration between statutory and voluntary agencies. The community care reforms will mean that agencies throughout Britain will have to collaborate in similar ways. While the mechanisms of joint planning will be familiar to many, joint working—passing referrals, swapping caseloads, and establishing networks of expertise—will be almost universally new.

If new services are to be sensitive to users' needs then disabled people must be included at the earliest stages of consultation and planning. The reforms will not mean much if they do not lead to tangibly improved care. Most users will not be concerned with the finer points of needs assessment, care plans, and care packages, but if the hands on service is no better than before they will want to know why.

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