

The costs of independent living

Important developments, such as direct payments and the move away from rigid use of in-house local authority services, have widened the options for many severely disabled people, but there are growing tensions between raised expectations and ever tightening constraints on expenditure.

Research led by Ann Kestenbaum found:

- f** There are wide discrepancies between the outcomes for disabled people with similarly high needs depending on where they live and when their support packages were first set up. Some people are inappropriately in residential care.
- f** Social services budget constraints have led to the imposition of ceilings for expenditure on individual community care packages. These are set with reference to costs of residential care and Independent Living Fund (ILF) rules.
- f** The ILF 93 Fund maximum 'ceilings' have remained unchanged since 1993, whereas costs have increased with wage inflation and changes such as Working Times Regulations and the stricter implementation of lifting restrictions.
- f** Some high support packages are complex patchworks of provision determined more by professional rules and timetables than the choice of the user. Packages operated through direct payments can offer a sharp contrast in achieving a more seamless service.
- f** Two particular barriers operate to prevent more flexible working between health and social services to the advantage of people with high support needs: (i) social care is subject to charges whereas NHS provision is not, and (ii) the NHS is unable to use its resources to fund direct payments.
- f** Direct payments have opened up opportunities for social activity through their flexibility and acknowledgement of disabled people's aspirations for independent living. But the rationing of services has meant that funding for anything other than securing the person's safety in their own home is being squeezed out.
- f** Social services' categorisation of people over 65 as 'elderly' and subject to different rules usually means lower ceilings on community care expenditure and more rigidity in their application. Over 65s have not been able to get top-up funding from the ILF since 1993, nor yet been able to access direct payments.

The last decade has seen major developments benefiting severely disabled people who choose to live in the community rather than in residential care. The operation of the ILF (see box) and, more recently, local authority direct payments have been two of the most significant. But policies and practices reflect increasing pressures on the budgets of funding agencies, in particular social service departments and health authorities.

This research aimed to provide some insight into factors that should be taken into account in debates about who should fund expensive community care packages and how funding and provision might be better co-ordinated and delivered.

The Independent Living Funds (ILFs)

The ILFs are government-funded discretionary trusts which provide financial help to severely disabled people so that they can buy personal and domestic assistance in the community rather than live in residential care. The Extension Fund continues paying awards to clients of the original ILF which closed in 1993 when new community care legislation was implemented. It currently has approximately 10,000 clients and accepts no new applicants. The 93 Fund was set up to take on new applicants, making awards to 'top-up' social services provision where the latter is worth at least £200 a week. Applicants must be between 16 and 66 years of age and be in receipt of the highest care component of the Disability Living Allowance. Awards are means-tested. The 93 Fund currently has approximately 5,000 clients.

High cost packages

There are various reasons why some disabled people's community care packages are particularly expensive. Apart from the number of hours of assistance required and the unavailability, or inappropriateness, of unpaid care, other important factors include the need for night-time cover, the impracticality of cheaper live-in arrangements, and the need for more than one assistant at a time (increasingly the case because of stricter implementation of lifting regulations). High travel costs in rural areas are also significant.

Overall numbers of high cost packages cannot be ascertained because many social services departments do not record the total costs of individual packages where components such as in-house home care or day centre provision are accounted for under separate budgets. However, we know that the ILFs are involved

in supporting more than 4,000 packages (UK-wide) where the total cost is above £400 a week. In 650 cases, the Extension Fund alone is funding at least this amount. Others are jointly funded by the 93 Fund and local authorities.

An uneven spread of high level funding reflects variations in social services policies and practices. Considerable differences are apparent in how they use the 93 Fund, their attitudes towards paying more for community care than they might have to pay for residential care and also whether they are willing to pay for genuine independent living rather than just basic maintenance of people in their own homes. Budget constraints have a powerful impact on these decisions.

Budget constraints

Social services budget constraints have led to contractions in services and waiting lists for equipment, the prioritisation of crisis assessment over on-going support and review, and the imposition of ceilings for expenditure on individual community care packages.

Expenditure ceilings are set with reference to the cost of residential/nursing home care, but also with reference to the way the ILF operates. The 93 Fund's threshold of £200 for social services contributions before it will provide 'top-up' funding, its maximum of £300 for that top-up, and the £500 ceiling it imposes nationally on the joint cost of any new packages, have a significant impact. These levels have not changed since 1993, taking no account of general inflation, changes in employment legislation or variations in local costs.

Sometimes there is an incentive for social services to use in-house home care or day centre provision because they may not be subject to critical community care budget ceilings. Day centre provision may not be ideal but may make the ILF threshold easier to reach.

Social services have to consider spending more than £200 a week where a person is not eligible for the ILF, where such an application is not appropriate, or where the ILF is contributing its maximum but costs are rising above £500. They have to consider covering the full cost of packages assessed at over £500 if there is not already an ILF contribution.

The limit of £500, because it is so low, causes conflict between Social Services and ourselves. We have to get involved in so many situations where disabled people are unhappy with their care package because it is inadequate. It also demoralises social workers who feel they cannot do a good job within the financial

constraints placed upon them. [Manager of a local disabled people's organisation]

Ceilings are imposed less rigidly for people under 65 than for older people, but care managers now have much less discretion than previously to agree high cost packages.

The 'in-house first' policy operated by some authorities tends to be applied less rigidly to under-65s but, where applied, the inflexibility of the service is significant. Disabled people's experience of independent sector agencies is mixed. There is sometimes concern about restricted lists of accredited agencies and their effect on social workers' ability to arrange high support packages, and also on the outcomes for disabled people forced to change to cheaper agencies.

I was with another agency which paid their helpers more and seemed to get a slightly higher quality of carer. But they put their prices up and Social Services wouldn't increase their money, so I had to swap agencies.

Continuing care funding

Provision for people with high support needs varies considerably according to how continuing care criteria are applied locally.

NHS financial support for some services can allow someone with needs assessed by social services as costing more than £500 a week to access the assistance they need rather than go into residential care; the ILF £500 ceiling ignores health funding. Some personal assistance packages are supported for as much as £1,000 or more a week because health money is made available.

Even where the need for a flexible approach to joint local/health authority funding is acknowledged strategically, however, the structures often inhibit best value solutions. Apart from jealously guarded budgets and professional roles, two particular barriers are presented:

- social care is subject to charges whereas NHS provision is not, and
- the NHS is unable to use its resources to fund direct payments.

The continuing care criteria were written by the health authority and are so tight that hardly anyone who isn't in a nursing home or dying can get help. [Senior SSD manager]

The barriers are not insurmountable, however; in one authority direct payments, funded from both sources,

have been used to successfully support a seamless provision of assistance.

Independent living

Some people are in residential care against their will because of a failure of social services and health authorities to agree the funding for community care. Others are there because different local authorities dispute their responsibility for funding. There are also worrying indications that people are placed in cheaper but inappropriate nursing homes because of local authority budget constraints.

A prerequisite for affordable independent living is suitably adapted housing, with room for assistants and equipment as necessary. Scarcity of suitable properties, waiting lists for adaptations and lack of involvement of disabled people themselves in designing the environments they need make this extremely difficult to secure.

Live-in support can be cheaper and may be ideal if the person wants younger assistants. But it is not always feasible because of housing conditions, or recruitment problems. Also, it may not be desirable, privacy being a quality that people with high support needs tend often to be denied yet value highly.

Some care packages are complex patchworks of provision which may have evolved over a number of years as circumstances have changed. Alternatively, they may be the consequence of restrictive practices of different funding agencies, for example where social services provide in-house services, the ILF pays for the person to buy personal assistance, and the district nurses perform tasks that might otherwise be carried out by someone other than a qualified nurse.

It's rather like I'm institutionalised in my own home. That's how I feel. It's times for this, times for that, certain times to get up, certain times to go to bed, whether you want to or not. I can't have any say about the times the nurses come ... What I miss is quality time.

Two contradictory trends affect the funding of support for social activity. One is the contraction of services which means that funding for anything other than securing the person's safety in their own home is being squeezed out. Services that shop for someone rather than accompany them shopping for themselves would, for example, be offered. The other trend, however, is that direct payments packages are opening up opportunities for social activity through their flexibility and their acknowledgement of disabled people's aspirations for independent living.

The ILF has often been the only means by which people with high support needs have been able to access enough funding for personal care to be able to use it flexibly and thereby support social activity outside their homes. But getting the £200 worth of support from social services to open this door can sometimes be easier for people with learning difficulties who attend day centres all week than for people with physical disabilities for whom day centre provision is unattractive.

Respite which offers carers a break from their normal routine but which also gives disabled people the opportunity of a proper holiday rather than a spell in inappropriate residential care seems to be unusual.

It's really good that Social Services were able to look at the problems and say yes. What do I want to go and pay residential for? I've got young personal assistants and one of them came to Blackpool with me. I had a proper holiday.

People have varying levels of need for professional care management, but the minimum requirement of a familiar and easily accessible contact within social services is not always available. Specialist physical disability social workers are valued for their knowledge and sensitivity to independent living issues. Well-resourced direct payments support services are valued for their encouragement and support. At the other end of the spectrum, communication channels can be poor and direct payments badly resourced and supported.

I said to the lady at the town hall 'Why don't you have an awareness week?' [about direct payments] And they said 'It would be dreadful to make them aware and then we can't give it to them'

Independent living for over-65s?

Disabled people over 65 are categorised as 'elderly' or 'older people' which usually means lower and more rigidly applied ceilings on community care expenditure. They have not been able to get top-up funding from the ILF since 1993, nor to access local authority direct payments, although the Government has announced its intention of making the latter a legal possibility in the near future.

Conclusion

Putting choice and control, together with fairness, at the heart of services is clearly a difficult challenge for social care managers with inadequate budgets, but there are better ways of using resources for people with

high support needs than some of the current arrangements observed in this study. Other packages of assistance show what is possible when user-defined outcomes are given priority over traditional practices and service provider boundaries.

About the study

The project was carried out between 1997 and 1999, led by Ann Kestenbaum working with The Disablement Income Group and with the support of the ILFs. It covered six local authorities, two in the North, three in the Midlands and one in London. Fifty staff from social services departments and health authorities and 12 from voluntary sector organisations were interviewed. Fifty-eight disabled people whose support packages cost more than £400 a week and who lived in those areas were subsequently interviewed.

How to get further information

The full report, **What price independence? Independent living and people with high support needs** by Ann Kestenbaum, is published for the Foundation by The Policy Press in association with *Community Care* magazine (ISBN 1 86134 203 9, price £13.95). A disk version is available direct from The Policy Press, University of Bristol, 34 Tyndalls Park Road, Bristol BS8 1PY, Tel: 0117 954 6800 (price £13.95 + £2 p&p).